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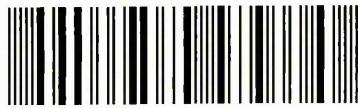
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**An Ethnographic Study of Support groups; the Pain Accounts of Older
Members
(Volume 1)**

Paul Sykes

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Abstract

The government of the United Kingdom (UK) has signalled that people with long term conditions such as chronic pain should be supported to self manage their conditions. A review of the literature reports that self management of chronic pain can impact on the psychological and physical well being of those who are experiencing long term painful conditions. The UK government (DoH, 2001) suggests that support groups can help recruit participants to self management courses such as the Expert Patient Programme and Challenging Arthritis. The government (DoH, 2001) also recognises the importance of local access to self care information and support networks that support groups can offer. However review of the literature reveals that support groups can offer more and have an impact on the psychological as well as physical wellbeing of those experiencing chronic pain. The literature also revealed that there has been little research into the impact of support group memberships on the lives of older adults. Increasing the knowledge of the functions of support groups can be used to offer older adults choice and help motivate them to become members of support groups. The socially constructed definition of older adults defined in the National Service Framework (DoH, 2001) includes those who are aged 55 years or older and will be used in this current study.

The aims of this study are:

- To identify the purpose of support groups from the perspective of older adults members
- To determine the motivation and routes that are taken by older adults to join support groups.
- To explore the provision within support groups of the four elements of social support identified by Langford et al (1997) which include; informational, emotional, appraisal and instrumental.
- To examine the impact that support group membership has on the chronic pain self management activities of older adults.
- To identify the location within an individual's chronic pain trajectory of when they are likely to benefit from group membership group members.

This ethnographic study used participant observation and semi-structured interviews to generate accounts of older adults' perspectives of support groups. To prevent authoritarianism a partial feminist approach was used. Purposive sampling was used to select older adult participants (=9) from three chronic illness support groups. Schema analysis (Ryan and Bernard, 2003) was used to collapse the data into thematic groups, schema analysis has similarities to grounded theory (Strauss and Corbin, 1998) in that it discovers links themes into theoretical models.

The sampled support groups in this study had representation of older adults but this was limited to white Irish or white British despite being located in areas with diverse ethnic populations. There was also an identification of a core group of members in each of the sampled groups. The core group consisted of members who attended the meeting regularly and contributed to the voluntary activities of the group as well as the committees.

The data analysis from the interviews revealed that participants were also experiencing co-morbid illnesses and these were not reported as being bothersome and were affectively self managed by the individual. The perceived dominant illness was one of the motivating factors for joining the support group. There was also evidence of perseverance, living life despite the chronic pain and locus of control. The motivation to join the support group had already been reported in the literature such as a response to an information deficit, social networking and starting the group and recommendations by healthcare professionals. However there was also evidence of philanthropy which has not previously been reported, this impacted positively on the participants quality of life because of their ability to contribute within society. The interviews also identified three selves within the chronic pain trajectory including; *the past self*, *the chronic pain self* and *the present self*. The present self is identified as the location within the chronic pain trajectory which benefits from support group membership.

The provision of social support offered by the groups consisted of four components (Langford et al, 1997) which are informational, emotional, instrumental and appraisal support. Previous support group studies have only focused on informational and social support which has been reported separately.

This thesis adds to the body of knowledge about the activities of support groups for long term conditions and their contribution to the support of older adults experiencing painful conditions. New findings suggest that support groups can be affective at certain points within the chronic pain trajectory and that co-morbid illnesses are demonstrated to be effectively managed by the individual. The findings also identify the social support activities that have not been previously reported in the reviewed literature but are present within support groups.

Contents

Abstract	2
Contents	5
Figures	15
Tables.....	17
Chapter 1 – Introduction	18
Chapter 2 – Chronic Non – Malignant Pain	27
2.1 Introduction.....	27
2.2 Selective Overview of the Literature	27
2.2.1 Population	30
2.2.2 Policy/Strategy	30
2.2.3 Consequences.....	31
2.2.4 Study Design.....	31
Summary	33
2.3 Pain Demographics	33
2.3.2 Prevalence of Chronic Pain in the United Kingdom.....	34
2.3.3 Older Adults.....	34
2.3.4 Pain in Older Adults	36
2.3.5 Pain and gender.....	39
Summary	43
2.4 Chronic Cancer Pain	43
2.5 Acute Pain and Chronic Pain	45
2.5.1 Progression of Acute to Chronic Pain.....	48

2.5.2 Chronic Pain as a Consequence of Chronic Illness	52
Summary	53
2.6 Pain Theories	53
2.6.1 The Gate Control Theory (GCT)	55
2.6.2 Neuromatrix Theory of Pain	57
2.6.3 Biopsychosocial Model of Chronic Pain	59
Summary	62
2.7 Social Aspects of Pain	63
2.7.2 Pain Descriptions	70
2.7.3 Pain Perceptions.....	71
2.7.4 Attitudes of others.....	71
2.7.5 Learned Helplessness.....	74
Summary	75
2.8 Psychology of Pain	76
2.8.2 Catastrophising	79
2.8.3 Fear Avoidance	82
2.8.4 Anxiety.....	82
2.8.5 Depression	85
2.8.6 Self Efficacy	87
2.8.7 Locus of Control	91
2.8.8 Coping Strategies	93
Summary	94
Chapter Summary	95
Chapter 3 - Support Groups	97
3.1 Operational Definition of Groups to be studied.....	97

3.1.1. What is a support group?	98
3.1.2 Purpose of Support Groups.....	99
3.2 Support Group Literature.....	100
3.3 Support Groups in the United Kingdom	105
3.4 Issues with the Research of Groups.....	105
3.5 Chronic Pain Support Groups	106
Summary	111
3.5.1 Groups that offer general support	112
Summary	117
3.5.2 Self Management Programmes.....	117
Summary	122
3.6 Support Group Recruitment Strategy	123
3.7 Professional Involvement	125
Summary	130
3.8 Ethical considerations	131
3.9 Determining Factors for Participation in Support Groups.....	131
3.9.1 Social Support.....	132
3.9.2 Informational Support.....	138
3.9.3 Information Standard	142
3.9.4 Psychosocial Support.....	144
3.9.5 Helper-therapy Principle.....	150
3.9.6 Motivational Determinates	150
3.9.7 Previous Support Group Experience.....	151
3.9.8 Personal and Situational Factors	151
Summary	152

3.10 Benefits of Support Group Membership.....	153
3.11 Online Support Groups	159
3.11.1 Ethical issues.....	160
3.11.2 Internet Usage by Older Adults	161
Summary	163
3.12 Chapter Summary	163
Chapter 4.....	166
Section 1 – Aims and Research Questions	166
4.1 Theoretical Framework.....	166
4.1 The Research Question	170
4.2 Operational Definitions.....	171
Section 2 – Methodology	172
4.3 Methods Available	172
4.4 Constructionism	176
4.5 Ethnography	179
4.6 History of Ethnography	181
4.7 Inspiration and Influence from Traditional Paradigms.....	182
4.8 The Roles of the Ethnographer	184
4.9 Reflexivity	185
Conclusion	188
Chapter 5 - Methods	190

An Ethnographic Study of Support Groups; the Pain Accounts of Older Members 190

5.1 Introduction.....	190
5.2 Research Design	190
5.3 Justification of Method	192

5.3.1 Group Sampling	192
5.3.2 Data Collection	192
5.3.3 Participant Observations	193
5.3.4 Field Notes	194
5.3.5 Semi-structured Interviews	195
5.3.6 Trustworthiness.....	197
5.3.7 Authenticity	199
5.3.8 Generalisability	200
5.4 My Background and Observations	200
5.5 Methods	204
5.6 Location and Approach of Support Groups	204
5.6.1 Locating Support Groups.....	205
5.6.3 General Practitioner Surgeries	206
5.7 Ethics	209
5.7.1 Protection from Harm	210
5.7.2 Safety and Well Being of the Researcher	211
5.7.3 Consent	211
5.7.4 Data Protection and Management.....	212
5.8 Participant Observation.....	213
5.7.1 Field Notes	215
5.8 Interview Sampling Decisions	216
5.9 Data Collection	217
5.9.1 The Interview Schedule	217
5.9.2 Post Interview Memos	217
5.10 Trustworthiness.....	218

5.11 Authenticity	219
5.11.1 Fairness	219
5.11.2 Ontological Authenticity.....	220
5.11.3 Educative Authenticity	220
5.11.4 Catalytic Authenticity	220
5.12 Data Analysis.....	221
5.13 Coding.....	222
Chapter 6 – Study Findings	224
6.1 Study Findings: Field and Observations	225
6.2 Interview Participants	226
6.3 Group Demographics	227
6.3.1 Gender.....	228
6.3.2 Ethnicity	230
6.3.3 Age.....	231
6.3.4 Group Attendance	231
6.4 Core Group Members	237
6.5 Meeting Room Layout	237
Summary of Field Notes and Observations	240
Chapter 7 – Study Findings: Semi-Structured Interviews	243
7.1 The Interview Participants	244
7.1.1 Comorbid Chronic Illnesses.....	246
7.2 Psychological Approaches to Chronic Pain.....	249
7.2.1 Perseverance	249
7.2.2 ‘Living Life’	251
7.2.3 Locus of Control	255

7.3 Reasons for Group Participation.....	258
7.3.1 Informational Deficit	259
7.3.2 Social Networking	262
7.3.3 Starting the Group.....	264
7.3.4. Medical professionals Recommendations.....	265
7.3.5 Philanthropy.....	266
7.4 The Identification of <i>Three Selves</i> of Chronic Pain.....	269
7.4.1 The Past Self.....	274
7.4.2 The Chronic Pain Self.....	276
7.4.3 The Present Self	280
Summary of the Participant Accounts	284
Chapter 8 – Study Findings: Social Support.....	286
8.1 Informational Support.....	288
8.1.1 Information Support Prior to Group Membership	289
8.1.2 Written Information	293
8.1.3 Guest Speakers.....	300
8.1.4 Chronic Pain Discussions	304
Summary of Informational Support Findings	306
8.2 Emotional Support	307
8.2.1 In-group support	308
8.2.2. Out group support	309
8.2.3 Relationships with non- group members	311
8.2.4 Support need of Partners and Carers.....	314
Summary of Emotional Support Findings	318
8.3 Appraisal Support	319

Summary of Appraisal Support	321
8.4 Instrumental Support.....	321
8.4.1 Communicating with Medical Professionals	322
8.4.2 Challenging Arthritis	325
8.4.3 Group Welfare Officer.....	326
8.4.5 Informal Group Outreach.....	327
8.4.6 Telephone Helpline.....	328
8.4.7 Newsletters.....	330
Summary of Instrumental Support.....	331
8.5 Summary of Social Support Findings	333
8.6 Summary of Key Findings and Contribution to Existing Knowledge.....	336
8.6.1 Group Demographics.....	337
8.6.2 Existence of Core Members.....	340
8.6.3 Impact of Layout of Meeting Rooms.....	342
8.6.4 Co-morbid Illnesses	344
8.6.5 The Three Selves of Chronic Pain	344
Chapter 9 – Discussions and Study Limitations	349
9.1 Study Limitations.....	349
9.2 Research Role	352
9.2.1 The Group Leaders' Interpretation of my role within the Groups.....	354
9.3 Locating Support Groups.....	355
9.4 The Sampled Groups	355
9.4.1 The Research Communities Relationship with Support Groups	355
9.4.2 Security of Group Members	357
9.4.3 Language Used in Groups.....	357

9.4.4 Sampled Groups Characteristics	357
9.5 Obtaining Group Consent	357
9.6 Interview Participant Sampling.....	359
9.7 Negotiating Departure.....	362
9.9 Generalisability	363
9.10 Data Protection and Management.....	363
9.11 Reflection on Learning	364
Chapter 10 – Broadcasting the Results	366
10.1 Broadcasting the Results – An Ongoing Process.....	367
10.2 Broadcasting the Results in Academic Settings	367
10.3 Arthritis Care	370
10.4 Challenges to Broadcasting the Results – Group Closure	370
10.4.1 MS Group	370
10.4.2 Fibromyalgia Group.....	371
10.5 Broadcasting the Results Further Afield.....	372
Chapter 11 – Conclusions	374
11.1 Motivation to Join a Support Group	375
11.1.1 The Three Selves of Chronic Pain	376
11.1.2 Information Seeking	376
11.1.3 Increase in Social Network	377
11.1.4 Healthcare Professional Recommendation	378
11.1.5 Starting a Support Group	378
11.1.6 Philanthropy.....	379
11.3 Benefits of Group Membership	379
11.4 The Sampled Groups	380

11.5 Future Research	382
References.....	385
Appendix 1 - Cognitive Coping Strategies	406
Appendix 2 - Letter to Support Groups	407
Appendix 3 – The Interview Schedule.....	409
Appendix 4 – Sample Transcript Analysis (information gathering Mary).....	410
Appendix 5 – Presentation to the Aberdeen Pain Group	413
Appendix 6 - Presentation Welsh Pain Society	418
Appendix 7 – Presentation to the British Pain Society Meeting.....	429

Figures

Figure 2.1 – The Base Literature Strategy for this Current Study	29
Figure 2.2 – The focus of the Literature Search for this Current Study	32
Figure 2.3 – The findings of the Kumar and Allcock (2008) report.....	39
Figure 2.4 – Psychosocial aspect of Pain.....	52
Figure 2.5 – Early Theory of Pain based in Descartes.....	54
Figure 2.6 – The Gate Control Theory (GCT)	56
Figure 2.7 – The Conceptual Model of the Biopsychosocial Interactive Processes in Health and illness.....	61
Figure 2.8 – Conditions for Mediation	74
Figure 2.9 – The Putative Associations of Catastrophising with Pain Outcomes	80
Figure 2.10 – The Fear Avoidance Model.....	84
Figure 3.1 – The Flow of the Support Group Literature.....	102
Figure 3.2 – The Outcome of Chronic Pain Support Group Participation	110
Figure 3.3 – The Self-Directed Group Work Model, Adapted for Chronic illness Support Groups	129
Figure 3.4 – Determining Factors in Joining a Support Groups	132
Figure 3.5 – The Four Broad Components of Social Support	133
Figure 3.6 – Reasons for not Joining and Perceived Outcomes of Those with Negative views of Support Groups	141
Figure 3.7 – The Information Standard Quality Mark.....	142
Figure 3.8 – The Information Standard Guidance	143
Figure 3.9 – The Psychosocial Variables and Perceived Outcomes of Support Group Participation	145

Figure 3.10 – Determining Factors Regarding Support Group Participation, Modified from Voerman et al (2007)	152
Figure 3.11 – Hypothesised Effects of the Variables Believed to Influence Adjustments to Illness	157
Figure 4.1 – The Theoretical Framework	166
Figure 4.2 – Gold’s Classification of Participant Observer Roles	184
Figure 5.1 – Overview of the Development of the Research Design	191
Figure 5.2 – The Sources used in Locating the Included Support Groups	208
Figure 5.3 – The Observation Checklist	214
Figure 5.4 – Organising, Coding, Writing, Theorising and Reading.....	223
Figure 6.1 – The Chapters and Themes in the Overall Framework	225
Figure 7.1 – Attitudes to Death and Dying	270
Figure 7.2 – A Diagrammatic Representation of the Three Selves of Chronic Pain	274
Figure 8.1 – The Four Components of Social Support Explored in this Study	288
Figure 8.2 – Instrumental Support Provision in the Sampled Groups	322
Figure 11.1 – The Purpose of Support Groups	375

Tables

Table 2.1 – The method used for the search strategy for this current study	28
Table 2.2 – Summary of the Biomedical Model of Illness	46
Table 2.3 – Early Pain Theories.....	53
Table 2.4 - How the Gate Control Theory differed from Previous Pain models.....	55
Table 2.5 - The Three Key Assumptions of the Neuromatrix Model.....	58
Table 3.1 – The Methods used for the Search Strategy of this Study.....	101
Table 3.2 – Questions for Researchers regarding Research Design.....	106
Table 3.3 – Types of Professional Involvement in Support Groups.....	125
Table 4.1 – The Six Characteristics of Ethnographic Research.....	180
Table 5.1 - Support Group Sampling.....	205
Table 5.2 – Search Results of General Practitioners.....	207
Table 5.3 - The Shortlist of Groups Suitable for Study.....	209
Table 5.4 – The 2003 data protection acts eight key principals.....	212
Table 5.5 – Inclusion and Exclusion of the Interview Participants.....	216
Table 6.1 – The Pseudonyms of the Interview Participants.....	227
Table 7.1 – The Interview Participants.....	245

Chapter 1 – Introduction

In the United Kingdom (UK) average life expectancy has grown dramatically over the last century, from 47 years in 1900 to around 80 years today (Medical Research Council (MRC), 2005). The Department of Health (DoH) in the UK reports that the population of people aged 65 years has more than doubled since the 1930s (DoH, 2001). According to the MRC (2005) the consequences of this longevity are that individuals will be exposed to a greater risk of experiencing degenerative diseases, frailty and dependence. They identify the importance of medical research which shows what affects older adults' mental and physical wellbeing has on their independence and quality of social relationships (MRC, 2005). The MRC concludes that when government policymakers are armed with such research they can draw up effective strategies for tackling problems. The UK Government has published various policy and strategy documents focusing on the challenges of an ageing population which includes the National Service Framework (NSF) for Older Adults (DoH, 2001).

In the United Kingdom there are currently 5 million people aged 65 years and older who are in some degree of pain and discomfort (Kumar and Allcock, 2008). The University of Nottingham, Help the Aged and The British Pain Society have published a report with a focus of the consequences of pain in older people (Kumar and Allcock, 2008). The report recognises that the impact of chronic pain on the health and social care systems of the UK is significant and of great concern (Kumar and Allcock, 2008). Additionally they report that pain in older people is an increasingly important health issue requiring urgent attention.

A specified aim of the report is to raise awareness of pain in older adults by challenging current attitudes and beliefs that chronic pain is a consequence of ageing and therefore regarded as normal in later life. The current situation has led to older adults suffering chronic pain because they do not necessarily receive the appropriate assessment and treatment (Kumar and Allcock, 2008).

In response to the challenges posed by an ageing population with an associated increase in long-term or chronic conditions including pain, the UK government has shown interest in self care and self management strategies. This includes adoption of the chronic disease self management programme (CDSMP). In the UK the government has named the CDSMP, the Expert Patient Programme (EPP). The UK national charity Arthritis Care runs an identical course called Challenging Arthritis. Investment in supporting self care is reported to potentially reduce visits to General Practitioners by 40%, outpatient clinics by 17%, Accident and Emergency departments by 50% and reduce drug expenditure by an undisclosed amount (DoH, 2001). However, the EPP is not without criticism within the literature with Koch et al (2004) arguing that the *self* is often missing from self management courses, describing them as off the shelf and prescriptive. The EPP is also reported to be expensive with a large number of drop outs as well as failure to engage with the recommendations (Kerns and Habib, 2004). The government of the UK also recognises the importance of locally available information and support (DoH, 2001). There is also the suggestion that support groups can be a source for recruiting participants to self management courses such as the EPP. However there is no discussion regarding the reasons why individuals become members of these groups and the support that is available from them.

Support groups have similarities with self management programmes and support groups in that they are both led by lay members (Barlow et al, 2000; Charlton and Barrow, 2002). However, support groups can have minimal or no professional input (Adamsen and Rasmussen, 2001) in contrast to self management programmes which are described as crossing the professional-led/user-led spectrum (DoH, 2001). The most striking differences concerns membership, support groups have open membership (Charlton and Barrow, 2002) which means that attendance at meetings and length of membership is flexible.

In the UK there is little reliable population data available regarding the number of support groups in existence. In 2000 it was estimated that there were approximately 23400 support groups nationwide (Munn-Giddings and McVicar, 2006). In Nottingham where there is a register of support groups it was found that there were 259 groups, translating to 0.4 groups per 1000 of the population (Elsdon et al, 2000).

This study helps to contribute to the gap in knowledge regarding older adults and support groups membership. The limited literature focuses on groups that support those with Parkinson's and Alzheimer's disease with very little attention paid to chronic pain and long term painful conditions. There is currently only one study with a focus on chronic pain support groups (Subramaniam et al, 1999) but it is not specific to older adults. This current study is intended to increase the awareness of the purpose of support groups from the perspective of older adults. The aims are to determine the motivation and routes to joining support groups. To explore the provision of the four components of social support (Langford et al, 1997).

To report the impact that group membership may have on the self management and support activities of older adults and finally locate when in the illness trajectory support group membership could be beneficial for individuals.

Chapter two will report the demographics and the incidence of chronic pain in the United Kingdom (UK) and Europe. The recent policies/strategies of the UK government approach to the management of chronic pain. The chapter will explore the impact of acute, cancer and non-malignant pain and will report further on the choice to exclude cancer pain as the focus for this current study. The various models/frameworks for chronic pain will also be explored including; the biomedical models of pain (where a symptom or an illness is considered to have an underlying symptom that may be cured through medical intervention (Morrison and Bennet, 2006), the gate control theory (Melzack and Wall, 1965) and neuromatrix theory (Melzack, 1999) and biopsychosocial model of pain (which accepts that many illnesses have an underlying cause but they also elicit uniquely individual responses due to the action of the mind (Morrison and Bennet, 2006). The current definition of pain and the population I intend to study will be identified. The remainder of chapter will review the literature regarding the impact of chronic pain on older adults including psychological and social wellbeing.

The third chapter will identify the operational definition of the groups I intend to study by describing the differences between self management, self help and support groups. There will be an exploration of the limited chronic pain, long term painful conditions and cancer support group literature. This chapter will also report on support groups in the United Kingdom, issues with studying groups and the motivational factors in joining groups.

Social support is identified by Langford et al (1997) as instrumental, informational, appraisal and emotional support, however only information and social support are the focus of the reviewed literature.

Chapter four is divided in to two sections, the first presents the main research and the subsidiary questions and the aims of this study. This first section also presents the theoretical framework regarding pain and the management of pain including support group participation. Finally this section presents the operational definitions of older adults, support groups and social support. In the second section the methodological approaches that are available to answer the research questions of this study are discussed. The decision to employ a partial feminist ethnographical approach is explored later in section two including the roles of the ethnographer, reflexivity, ethical issues with qualitative data and protecting participants from harm.

Chapter five will initially present the research design and a justification of the choice of methodological approach. This section of the chapter will also discuss group sampling, data collection, participant observations, the purpose and use of field notes and the approach of the semi-structured interviews. There will also be discussions on the need to ensure trustworthiness, authenticity and generalisability. In the final part of this section of the chapter my background and observations will be presented. In the remainder of this chapter the methodological approach of locating support groups including online and primary and secondary care searches, enquires made with charitable organisation that focus on the care of older adults and local and central library's as well as approaches to known contacts of the supervisory team will be discussed. The methods of employing a local search will also be presented.

The ethics of the study are also reported including my safety and wellbeing and approaches to obtaining consent from the members of the sampled groups as well as the interview participants. The participant observation of the group meetings will include the use of field notes and the observational checklist which was developed for this current study. Data collection discussions will also include interview sampling decisions and the use of the interview schedule and post interview memos. The coding and analysis and the approach to trustworthiness and authenticity which is a key component of credible research will also be reported in this chapter.

The findings of this current study are presented in chapters six, seven and eight. Initially chapter six will report on the content of the findings chapters as well as the themes in the overall framework from the findings of this study. The remainder of chapter six will present the ethnographic perspectives of the studied groups this includes the group demographics; gender, ethnicity, age and attendance of members. Biographical information and the pseudonyms used for the interview participants will also be presented. This chapter will also discuss the presence of a core group of members which are defined as individuals who attend meetings regularly and who involve themselves in a number of group activities. The layout of the meeting rooms for each of the sampled groups was identified as an important aspect of this study and this will be discussed in chapter six.

Chapter seven reports the findings from the interview accounts of the older adult group members. The data from the accounts identified the presences of primary and secondary long-term conditions and these had an impact for some of the participants in respect of medical consultations.

The primary illness is identified as the motivational factor for participation in the support group. The secondary illness is reported by the participants as being managed well by them. Chapter seven will also report on the motivation of the interview participants to become members of the support group. In addition to information seeking, social networking, starting a group and joining on the recommendation of healthcare professional, these was also evidence of philanthropic reasons. In addition the interview participant reported that there was more than one reason for the decision to participant in a support group. The final part of chapter seven will discuss the identification of the three selves in the chronic pain trajectory. The identification of these selves also impacted on the continuation of support group membership.

Chapter eight will discuss the social support offered by the groups using headings from the four components identified by Langford et al (1997) including appraisal, emotional, instrumental and informational support. The final section of this chapter will summarise the key findings of this study and their contribution to the existing body of knowledge regarding support groups.

Chapter nine will discuss aspects of this study and also report the limitations of this study these include locating the groups and the relationship of the research community with support groups. The chapter will also report on my ethnographic role and the interpretation of my role by the group leaders. There will also be a discussion on the negotiations used when departing the field as well as approaches towards generalisability. The data protection and management used in this study will also be reported. In the final section of this chapter I will reflect on what I learned from conducting this ethnographic study.

Chapter ten report on how the findings of this study have or are intended to be broadcasted. This includes the identification of the importance of broadcasting information as an ongoing process due to the closure of two of the support groups. Presenting the results in three academic settings including the annual meetings of the Aberdeen Pain Group, Welsh Pain Society and British Pain Society, the results of presenting in these setting has impacted on the development of further research. This chapter also reports on the potential to broadcast the findings to the Patients Association, which is currently focused on the care needs of older adults as well as the patient research group INVOLVE.

Chapter eleven reports the conclusion of this study which has highlighted a wide variation of how groups function while identifying key elements recognised as important by group members. These include access to good quality information as well as the impact that socialisation has on the quality of life. There was also recognition that group membership can have an impact on an active retirement through the pursuit of group activities such as fundraising, this can also impact on the quality of life of older adults. Future research could be carried out to see if the different, perhaps less formal and more slow paced format of support groups could be a more acceptable method of delivering self management training for some older adults with chronic pain in comparison to self management programmes. There is also future scope to study how support groups and self management programmes may complement each other.

The identification of the three selves of chronic pain could be developed further to identify group members who are likely to engage in self management programmes which are currently reported by Kerns and Habib (2004) as expensive, have a high dropout and a failure of the participant to engage with the recommendations.

In addition a qualitative study could be conducted to explore that range of awareness of healthcare professionals and their opinions of current and potential roles of support groups for older adults with chronic pain.

Chapter 2 – Chronic Non – Malignant Pain

2.1 Introduction

This chapter will aim to explore chronic pain and various models and framework used to explain the phenomena. I will also discuss the current definition of pain and I will define the age range of the population I intend to study. This will set the scene for my research project which is an ethnographic study of support groups and the pain accounts of older adult members.

This chapter will also discuss the chronic pain demographics to illustrate the gender, age and extent of people experiencing chronic pain in the United Kingdom (UK) and across Europe. The chapter will review the chronic pain literature to help identify aspects of the chronic pain experience that could motivate older adults to join a support group. Support groups are described by Hatzidimitriadou (2002) as *another form of treatment* and will be discussed in chapter three.

2.2 Selective Overview of the Literature

Defining what is meant by older adults is complex with differing definitions within the literature. According to the World Health Organisation's definition older adults are those over the age of 60 years (WHO, 2007). This is in contrast to the socially-constructed definition of old age adopted by the government of the United Kingdom (UK) in their National Service Framework (DoH, 2001) which includes those who have reached retirement age, for males this is currently 65 years old and for females 60 years old (DoH, 2001) as well as people as young as 50.

The definition of chronic pain for this study is provided by the International Association for the Study of Pain (IASP) which declares that chronic benign pain is any pain that exists *beyond the expected healing time* (Merskey & Bogduk 1992). This is recognised as the gold standard in much of the pain literature.

The principal aim of the search for this current study was to identify the issues of chronic pain that could motivate an older adult into seeking help from a support group. The potential themes for the search were identified initially and included acute, cancer and non-malignant pain. Adjunct to this were the biomedical, psychological and social functioning of older adults and how pain may affect these. The major data-bases that were searched for this current study included CINAHL, Cochrane MEDLINE, Psychlit and the British Nursing Index and included literature between the years 1999 – 2009. It was anticipated that the literature prior to this date would be sparse or out of date. However there were exceptions to this criterion when the study was poignant such as the Gate Control Theory (Melzack and Wall, 1965). The search terms used for the review included: Older people, elderly, pain, chronic pain, biopsychosocial. The process for collection of the literature is presented in table 2.1.

Aspect	
Population	The population includes older people which is defined as those who are 55 years plus
Policy/Strategy	Studies that included the UK governments and National Charitable Organisations policy or strategy were also reviewed
Consequence	Studies that described the consequences of chronic pain on the biomedical, psychological and social well being of older adults were also included
Study Designs	All study designs were included

Table 2.1- The method used for the search strategy for this current study.

In addition the following criterion was used in assessing the suitability of the papers that were reviewed: 1) Is pain the central theme of the paper? 2) Does the paper have representation of older adults? The initial search strategy for this current study was presented within a framework in figure 2.1.

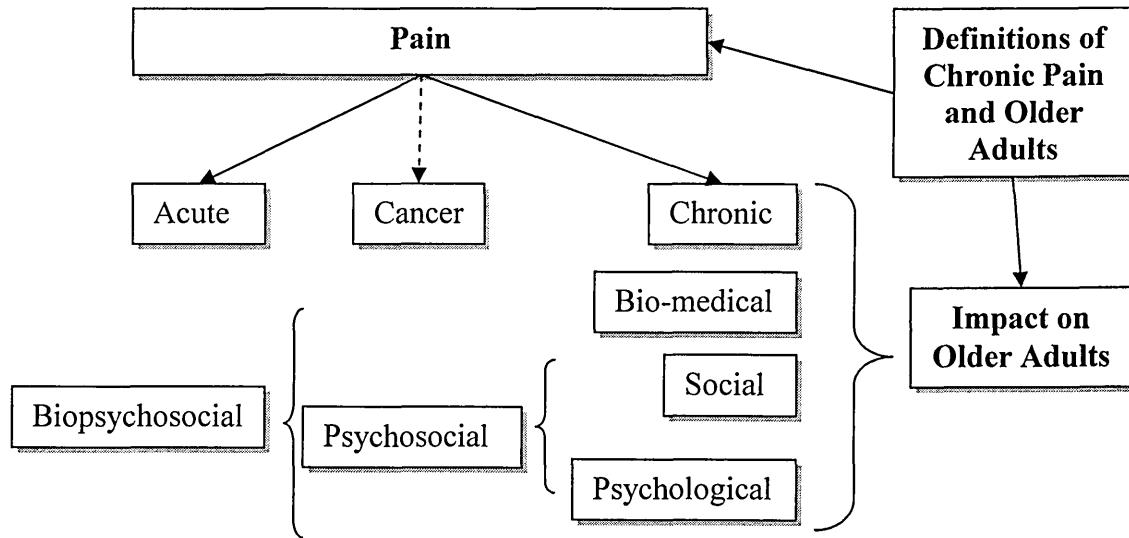


Figure 2.1 – The base literature strategy for this current study.

Figure 2.1 illustrates the baseline search strategy which included acute, cancer and non-malignant pain. The impact that acute pain has on an individual was searched to determine if there was always a progression to chronic pain. Cancer pain was not the focus of this , the reason for this exclusion discussed further on page 43, but some of the literature regarding cancer pain and in the search of support groups was helpful in further understanding what pain is and the support needs of the individual.

2.2.1 Population

The search included defining the age range which identifies older adults and would be used for this current study. Identification of what defines older adulthood is not straightforward as it is interchangeable throughout the literature as well as geographical locations. The socially constructed definition of older adults includes people as young as 50 or those who have reached the official retirement ages of 60 for women and 65 for men (DoH, 2001). The three nations of the United Kingdom with devolved powers define older adults as anyone over 50 (Scottish Executive, 2007; Welsh Assembly, 2007), and in Northern Ireland as anybody over the age of 60 (Northern Ireland Assembly, 2007). The issues of defining older adults are discussed further on page 34. Additionally the demographics and epidemiology of chronic pain in the United Kingdom and Europe was also reviewed. Papers that did not include adults aged 55 years and older were not included in the literature review.

2.2.2 Policy/Strategy

The search also included United Kingdom government and national charitable organisations policy/strategy documents regarding older adults with chronic pain/conditions. The policy and strategies included the National Service Framework for Older People (DoH, 2001), Ageing and Health (MRC, 2005), The Expert Patient Programme (DoH, 2001), Pain in Older People (Kumar and Allcock, 2008) which has been commissioned by Help the Aged and the British Pain Society.

2.2.3 Consequences

Figure 2.1 on page 29 presented the initial strategy for the literature search which focused on the biomedical, psychological and social issues of chronic pain. The search was managed by dividing pain into three distinct subthemes acute, cancer and chronic pain. The search also explored the biomedical models of pain, the gate control theory, neuromatrix theory and biopsychosocial model of pain.

2.2.4 Study Design

In the chronic pain search both qualitative and quantitative studies were included in the review. The focus of the strategy of reviewing the literature was further developed and this is presented in figure 2.2 on page 32. The strategy highlights the biomedical, psychological and social aspect of pain. The literature recognises that the consequences of pain should not be reviewed in isolation and that biomedical, psychological and social issues can impact on each other, for example anxiety can be described as a psychological issue but can impact on the social wellbeing of an individual which is described as a psychosocial issue.

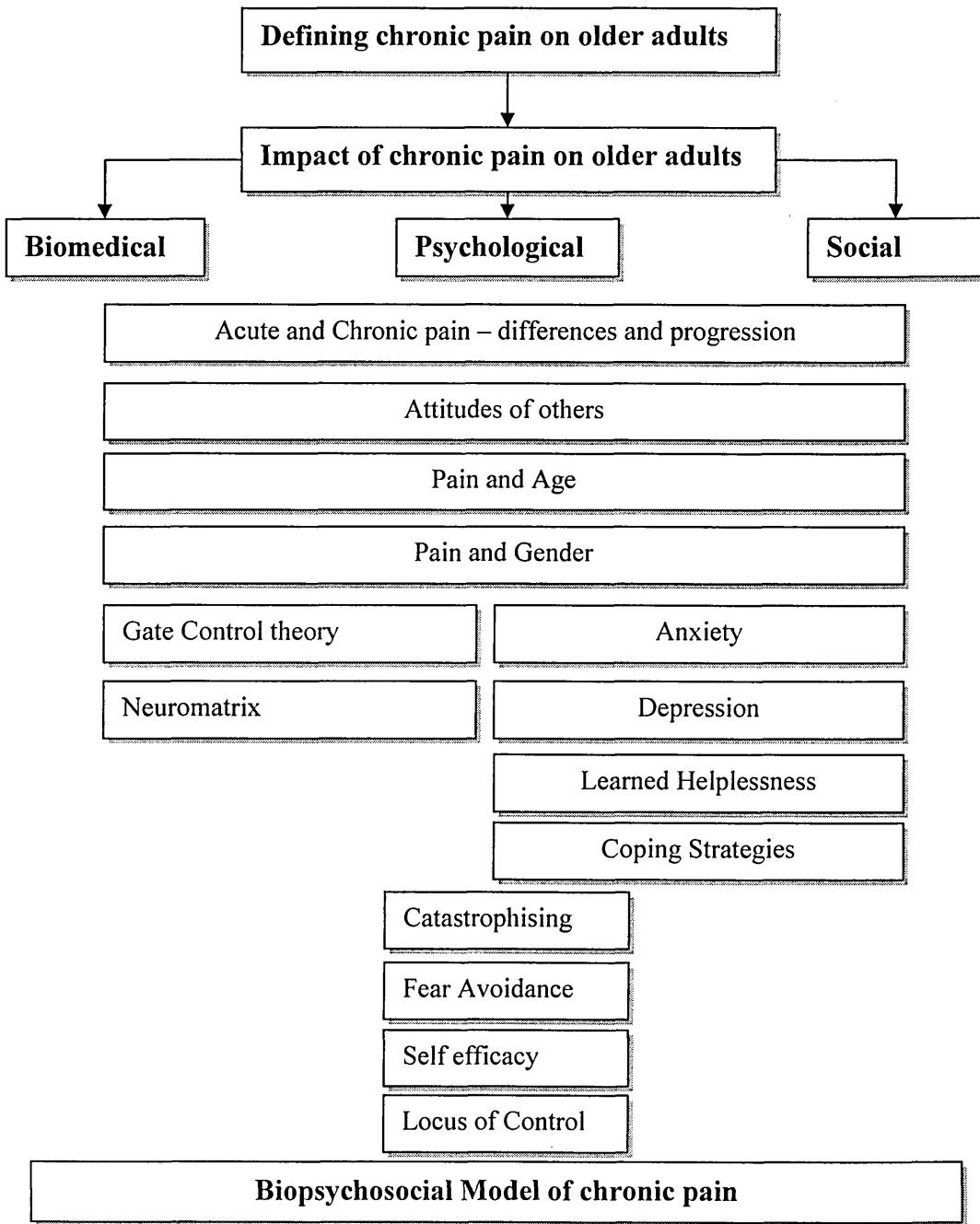


Figure 2.2 – the focus of the literature search for this current study.

Pain is now recognised as a multi-dimensional experience which is subjective in nature. This aspect of pain attracts literature from medical, psychological and social professionals. The results are that there is a vast quantity of pain literature. Therefore the search focused on the aspects and experience of chronic pain that may motivate an older adult to become a member of a support group e.g. coping issues, motivation to self management.

Summary

The literature search was conducted to recognise potential issues for older adults who are experiencing chronic pain. The search reviewed the biomedical, psychological and social effects of chronic pain. The review of the literature focused on the effects of chronic pain and how they may be motivational factors in joining a support group. The next section of the chapter will discuss the demographics of chronic pain which will recognise the numbers of people experiencing chronic pain in the UK and Europe, define older people for this current study and gender differences.

2.3 Pain Demographics

The demographics associated with chronic pain are presented here. This section of the chapter is important in understanding the scale of the issue. The UK government has responded to the increasing age of the population as well as planning for future costs to social and health services (DoH, 2001). Chronic pain is a major problem in the United Kingdom and comparable societies (Breivik et al, 2006) and as implications for health and social care resources as well as challenges to the quality of life of those experiencing it.

2.3.2 Prevalence of Chronic Pain in the United Kingdom

Estimates as to the prevalence of chronic pain are variable but epidemiological studies indicate that the incidence is generally large. Samwel et al (2007) suggest that chronic pain has a prevalence of 46% in Western countries. A population based study in the North West of England by Macfarlane et al (2001) suggests that in this geographical location the incidence of chronic pain is slightly higher. They surveyed a random sample of 6569 people aged 18 – 85 years old. They were asked the question “*During the past month have you experienced pain lasting at least one day?*” The results showed that 1005 people (15%) had widespread pain, 3176 people (48%) had regional pain and 2388 people (36%) had no pain at all. This study also reported that those with widespread pain were older and more likely to be female (median age 55 years; 66% women) than those with regional pain (median age 49 years; 59% women) and no pain (median age 42 years; 54% women). The overall results suggest that females are more likely to experience pain.

2.3.3 Older Adults

Older adults are the central characters of this study and this is because of recent strategies and policy documents from the UK Government such as the National Service Framework (DoH, 2001), charitable and other institutions in response to an ageing population (Kumar and Allcock, 2008). It is estimated in the United States of America (USA) that people 50 years and older are twice as likely to have been diagnosed with chronic pain (Gatchel et al, 2007) suggesting that the age cohort for this study will be the one that experiences issues with chronic pain the most. Although Wiesenfeld – Hallin (2005) posit that the gender difference in pain perception lessens with age but is maintained up until 65 years of age.

This phenomenon is explained further in the study by Zyczkowska et al (2007) which included a large cohort of centenarians and will be discussed further on page 38. As a consequence of an ageing society there is an increase in research of older adults in academia (Gatchel et al, 2007) and in the pharmaceutical industry as I observed during in my career there.

Despite the increase in interest on older adults, locating a definition of this section of society is not straight forward. The National Health Service (NHS) Research and Development strategic review (NHS, 1999) talks about older adults as those over 65 years old but does not state how it reaches this number. Throughout the document there are also frequent references to those aged 60 years and also those aged 50 years as being included in the review. This helps to illustrate issues with defining a reference point for this current study. The report for Help the Aged and the British Pain Society by Kumar and Allcock (2008) also does not define what is meant by older adults but makes frequent references to those over 65 years of age. The National Service Framework (DoH, 2001) reports that older adults are not a uniformed group but may be broadly seen as three groups, entering old age, transitional phase and frail older people. For those entering old age the report uses social-constructed definition of old age:

"These are the people [entering old age] who have completed their careers in paid employment and or/child rearing. This is a socially constructed definition of old age, which, according to different interpretations, includes people as young as 50, or from the official retirement ages of 60 for women and 65 for men." (DoH, 2001 page 3)

Those in the transitional phase are described as being in transition between a healthy, active life and frailty. The transition often occurs in the seventh or eighth decades but can occur at any stage of old age (DoH, 2001).

Frail older people are vulnerable as a result of health problems such as stroke or dementia, social care needs or a combination of both. This explanation helps some way towards clarity at this moment in time. The real issue is that what defines older age will be a moveable feast as advancements in health technologies continue to increase longevity. Already there is talk of an increase in the retirement age (Webster, 2009). This is however in response to a financial crisis and not necessarily a response to an increasingly ageing society. Although it is argued that there are elements from both standpoints (Webster, 2009).

This current study will use the socially-constructed definition of old age defined in the National Service Framework for Older People (DoH, 2001). For the purpose of this study older adults will include those who are aged 55 years or older.

2.3.4 Pain in Older Adults

The UK government reports that chronic diseases are more common among older adults (DoH, 2001). The estimates given are that two thirds to three quarters of all people aged over 75 years experience more than one longstanding condition – this is three times more than people aged 16-24 years (DoH, 2001). The figures by the Department of Health cover all longstanding conditions including epilepsy and diabetes but the report highlights the issues concerned with chronic pain such as that experienced with arthritis, ulcerative colitis and endometriosis.

The report also recognises that when faced with physical, mental and social restrictions individuals can experience anger, bitterness, depression and despair. Older people reported that pain can strip you of your dignity, among strangers in the street for example, it can also damage the close relationship with friends and families (Kumar and Allcock, 2008). Older adults recognise that pain is an immensely personal issue making it difficult for others to understand particularly if the person does not look ill (Kumar and Allcock, 2008). The pain can cause a barrier to socialising such as preventing a grandparent picking up a grandchild (Kumar and Allcock, 2008) which may impact on the quality of life.

The literature regarding the affects of chronic pain on older adults is mixed. In Breivik et al (2006) pan-European survey those below the age of 40 appeared to have less pain, whereas those aged 41 - 60 appeared to have the most pain. However the study did not attempt to reach older adults within nursing homes unlike the study by Zyczkowska et al (2007) discussed later in this section. The results of Breivik et al (2006) study reported pain was no more common in the oldest respondents to the survey than the younger respondents. This is in contrast to Sofaer et al. (2005) who suggest that one third of older people suffer chronic pain and many suffer chronic pain severe enough to interfere with their normal functioning. In a study by Rustøen et al (2005) regarding age and the experience of chronic pain it was found that there was no age difference in the intensity of the pain. In contrast to Zyczkowska et al (2007) report that the increased incidence of chronic diseases that older adults can experience has an elevated risk of them experiencing both acute and chronic pain.

The results of Zyczkowska et al (2007) study of the oldest old in both the community and institutional settings also found that an increase in the age of their participants decreased their mean pain scores. In addition to other participants aged 65 years and older, this study was fortunate enough to sample 800 older adults who were aged 100 years and older. Previous studies have used smaller samples of centenarians.

Zyczkowska et al (2007) offers two possible explanations for the decrease in mean pain scores that were observed in their study. Firstly, there may be survival biases which have resulted in an increased proportion of robust individuals at advanced years. Their relative absence of pain could reflect the fact that they represent a healthier elite subset of the population as the weaker members of this cohort have already died. Secondly the oldest old may report less chronic pain because they have *partly accepted it* and thus become accustomed to it. This may suggest that the oldest old report less pain due to an increase in stoicism (Yong et al, 2001) or because they adapt to pain by modifying their activities to reduce the likelihood of experiencing it.

The focus of this current research is older adults experiencing chronic pain; the focus of the UK governments National Service Framework (NSF) for the next 10 years is arthritis (DoH, 2001) which is recognised as a primary cause of chronic pain in older adults (Badley and Tennant, 1992, Brochet et al., 1998, Gold and Roberto, 2000; Rustøen at al., 2005). This current study is in response to the UK governments NSF (DoH, 2001) which has identified the social and medical issues of an ageing population with chronic medical conditions. Additionally a qualitative report jointly written by the UK charity Help the Aged, The British Pain Society and the University of Nottingham authored by Kumar and Allcock (2008).

This report conducted two listening events with 21 participants, the discussions revolved around the main issues and concerns relating to pain and older age. Although the sample size was small and it is emphasised in the report that it is not representative the intention is that emergent themes (figure 2.3) would help stimulate further debate and help shape services and support to meet the needs of older adults (Kumar and Allcock, 2008). The report helps to highlight what it is like to live with pain in older age and helped to shape some of the themes for this current study including; *quality of life, social, physical and emotional elements*.

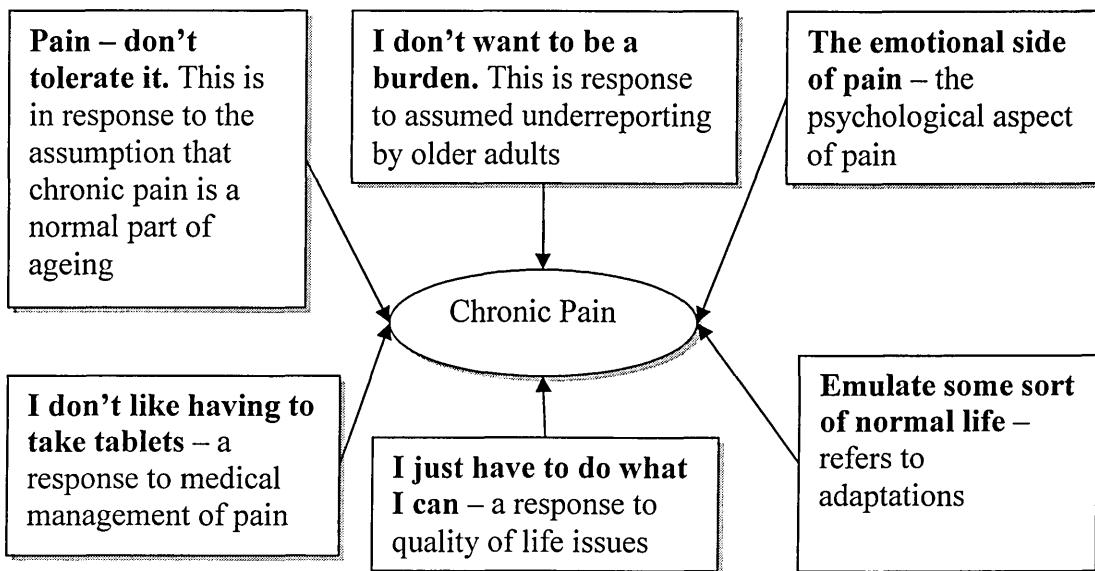


Figure 2.3: the findings of the Kumar and Allcock (2008) report

2.3.5 Pain and gender

Similar to the findings by Macfarlane et al (2001) a pan European study by Breivik et al (2006) also showed that a high proportion of respondents (56%) experiencing chronic pain were women. There were more females with chronic pain in Ireland, France, Germany, Israel and the Netherlands (around 60%) and less in the United Kingdom, Austria and Spain (around 50%).

According to Courtenay (2000) men are more likely than women to experience severe chronic conditions and fatal diseases and to experience them at an earlier age.

Although Unruh (1996) reports that post pubescent women are more likely than men to experience a variety of recurrent pains. Women report more severe levels of pain, more frequent pain and pain for a longer duration than men (Unruh, 1996).

A possible explanation of why gender is a factor and not just a demographic variable in chronic pain is purported by Rollman and Lautenbacher (2001) as being due to the endocrine influences unique to women such as menstruation, oral contraceptive use, pregnancy and hysterectomy these have the potential to increase the risk of musculoskeletal disorders. However Morrison and Bennett (2006) suggest that women are socialised into a greater readiness to attend and to perceive bodily signs and symptoms. This is probably because of menstruation, but the evidence is mixed and appears to vary according to the symptom. Edwards et al. (2003) and Wiesenfeld – Hallin (2005) explain that although women attend medical consultations more is not necessarily related to a gender differences in symptom perceptions but more to do with the fact that women are better in reporting health concerns (Wijnhoven et al, 2006). Women are also more likely to consult with doctors about issues that do not represent sickness such as the menopause, pregnancy as well as oral contraceptives (Skevington, 1996).

Early work by Mechanic (1976) suggested that the different genders respond to sickness in different ways. Courtenay (2000) argues that men are more likely than women to adopt beliefs and behaviours that increase their risk. These include engaging in smoking, drug and alcohol abuse as well as violence, crime and sexual conquests. Although this aspect of masculinity is not adopted by all males, aspects of it are dominant and form this genders identity (Courtenay, 2000). Charmaz (1995) refers to this issue as *Men's Identity Dilemmas* which can influence the following oppositions: risking activity vs. forced positivity, remaining independent vs. becoming dependent, maintaining dominance vs. becoming subordinate, and preserving a public persona vs. acknowledging private feelings According to Courtenay (2000) research typically neglects to examine men and the health risks associated with men's gender.

Little is known why men engage in less healthy lifestyles and adopt fewer health promoting beliefs and behaviours. Courtenay (2000) further suggests that left unquestioned, men's shorter life span is often presumed to be natural and inevitable. Wijnhoven et al (2006) acknowledges that gender specific socialisation has resulted in variations of the willingness to be *self-disclosing*, the need for social approval, verbal skills, symptom awareness and a predisposition to take action in response to symptoms and exposure to health risks (Charmaz, 1995; Courtenay, 2000). Whatever the case it is acknowledged that gender socialisation exists into the extent that males and females are allowed to respond to bodily symptoms in different ways (Morrison and Bennett, 2006).

Females are the dominant gender in medically unexplained chronic pain conditions and they are more likely to receive a psychiatric/psychological diagnosis according to Malterud (2000). The difficulty of obtaining a diagnosis in medically unexplained conditions is closely bound up with the concepts of *delegitimation*, *legitimation* and *stigmatisation* as proposed by Richardson et al. (2005). Malterud (1992) states that health complaints with no corresponding pathological findings are most often seen in women. These are mostly chronic and disabling conditions and present with extensive and subjective symptoms which lack objective findings and causal explanations (Malterud 2000). *Illness without disease* is a well known medical phenomenon and people who are presenting with such symptoms share an urgent need to be taken seriously by health professionals and as well as their social networks. Women can be predisposed to pain causing conditions due to biological influences such as migraine. According to Wiesenfeld – Hallin (2005) migraine is more prevalent in pre-menopausal women. Other conditions include irritable bowel syndrome, temporomandibular disorder and pain associated with rheumatic disease. Men are more prone to cluster headaches and other chronic illnesses, they are twice as likely to experience heart disease and stroke (Charmaz 1995; Courtenay 2000) and die on average up to seven years earlier than women according to Courtenay (2000).

Summary

The literature recognises that in the UK and comparable societies the incidence of chronic pain is large. This has implications to cost and allocation of valuable health and social care resources (DoH, 2001; Kumar and Allcock, 2008). This section of the chapter recognised that older female adults are the cohort most likely to experience chronic pain, however it is important to recognise that males may experience chronic pain equal to females but the approach and reporting of pain differs between the genders (Unruh, 1996). Wiesenfeld – Hallin (2005) and Zyczkowska et al (2007) recognise that pain reporting equalises and even declines in the age cohort of 65 years and older. The review of the literature of chronic pain demographics suggests that the populations of the support groups for this current study would have high representations of women aged 55-65 years old.

2.4 Chronic Cancer Pain

It is recognised that those with non-malignant and cancer pain need multidisciplinary treatment and care (Fredheim et al, 2008), there are fundamental differences recognised in the literature (Fredheim et al, 2008 and Hølen et al, 2008). Fredheim et al (2008) reports that for those with cancer the focus maybe directed towards the prognosis, the type and role of treatment including the use of strong opioids as well as pathophysiological disease mechanisms. Additionally Hølen et al (2008) reports that there is a difference in the pain experienced by individuals with cancer and non-cancer with regards to pain quality, history, temporal and affective aspects of pain. Hølen et al (2008) also posits for those with cancer, pain may be one of many symptoms in contrast to some with chronic pain where this is the only symptom.

The study by Fredheim et al (2008) concluded that when measuring quality of life it was reported much lower in those with non-malignant pain. There were also reports of issues with cognitive functioning, more pain, sleep disturbances as well as poor physical, social and emotional functioning. Additionally Hølen et al's (2008) study participants with non-cancer pain reported more pain interference with psychological functioning with increasing pain intensity.

Although there is an increase in survival rates of those with cancer both the Fedhiem et al (2008) and the Hølen et al (2008) studies recognised that pain was the dominant symptom in the non-cancer pain participants and also that the participants had experienced the pain for a longer period of time.

The reported issues by the non-cancer participants in these two studies such as dominance and length of time experiencing the pain and its impact on quality of life as well as interference with cognitive and psychological functioning issues, increased pain, sleep issues and poorer physical, social and emotional functioning may be motivational factors in help-seeking in support groups. Therefore the focus of this study is non-malignant chronic pain.

2.5 Acute Pain and Chronic Pain

Pain is described by Aldrich and Eccleston (2000, pg 1631) and Råheim and Håland (2006) as a “*central and ubiquitous part of the human experience*”. Pain is not just a physical entity it can also be emotionally based as in *grief, loss or relationship breakdown*. As a physical entity, acute pain seems to have an obvious beneficial function (Ogden 2007) providing constant feedback about the body enabling us to adjust our behaviour in how we sleep and sit for example (Eysenck, 1998). Acute pain also acts as a warning sign that something is wrong, resulting in protective behaviour such as avoiding movement and lifting heavy objects (Eysenck, 1998; Morrison and Bennett, 2006; Ogden, 2007). Bullington et al (2003) describe acute pain as being a logical and important protective signal, the nature of which helps us to learn not to carry out certain activities for example, not to touch hot surfaces. As well as the beneficial properties of pain there are causal explanations, Ogden (2007) gives the example of childbirth; here the pain can be *intense* but it has clear *cause* and *consequence*.

Acute pain can also be recurrent (Morrison and Bennett, 2006) as in migraines; headaches and trigeminal neuralgia. Despite some of the *benefits* of acute pain described here; when it is experienced over a long period as occurs with chronic pain, it can feel destructive, problematic and difficult to ignore (Morrison and Bennett, 2006).

Although the intensity of the sensation felt during an acute pain episode should not be underestimated, it is known that this intensity will fade because of the actions of analgesics, interventions of health care professionals (Nielson, 2001) or recovery from disease or illness. Thus when an individual consults with the medical profession with a pain problem the plan of care is based around a biomedical framework (Ogden, 2007). The biomedical model assumes that all disease is the result of cellular abnormalities (Wade and Halligan, 2004; Ogden, 2007). Wade and Halligan (2004) further summarise the biomedical model and this is presented in the table 2.2

All illness and all symptoms and signs arise from an underlying abnormality within the body (usually in the functioning or structure of specific organs), referred to as a disease.
All disease give rise to symptoms, eventually if not initially, and although other factors may influence the consequences of the disease, they are not related to its development or manifestations.
Health is absence of disease.
Mental phenomena, such as emotional disturbance or delusions, are separate from and unrelated to other disturbances of bodily function.
The patient is a victim of circumstance with little or no responsibility for the presence or cause of the illness.
The patient is a passive recipient of treatment, although cooperation with treatment is expected.

Table 2.2 - Summary of the biomedical model of illness (Wade and Halligan, 2004)

Additionally the biomedical framework views pain as an automatic response to an external factor (Ogden, 2007). The biomedical framework is deficient in explaining and subsequently dealing with the complexity of pain (Vlaeyen and Crombez, 1999). The biomedical model is also inadequate in psychological impacts of pain such as recognising post traumatic stress disorder in soldiers in the First World War, who were often executed for perceived malingering (Wade and Halligan 2004). It is widely acknowledged in the chronic pain literature that for the majority of individual's, acute

pain will diminish once the injury or disease has resolved (Merskey & Bogduk, 1992).

However Horn and Munafò (1997) warn that pain should not be regarded as just an underlying physical pathology because in some circumstances psychological, social and behavioural factors may be of greater importance and relevance in the diagnosis and treatment than the tissue damage.

When we understand the differences between acute and chronic pain can we can recognise the psychological and social issues that separate them. Carter and Gillies (1998) proposes one possible explanation for our lack of understanding is made clearer when we identify an issue with the Western medical approach which assumes that the mind and body are separate (table 2.2, page 46). In addition, Horn and Munafò (1997) report that for some, acute and chronic pain is viewed as separate ends of a spectrum but by others as separate entities.

Main and Watson (1999) describe the development of painful and chronic disability as more than physiological factors but rather due to a complex chain of events involving the individual's perception, personality, social circumstances, gender, age and psychological approach. Although Horn and Munafò (1997) have suggested that recent research has moved away from personality as a construct. Now, instead the focus is on cognitive variables for potential explanations of pain behaviours. Including, identifying the cognitive elements that are mediators of behaviour and behaviour change.

2.5.1 Progression of Acute to Chronic Pain

The literature does recognise that there are certain situations where acute pain can progress on to chronic pain, such as chronic post operative pain (Callesen et al, 1999; Perkins and Kehlet, 2000; Bisgaard et al, 2005; Morrison and Bennett, 2006).

According to Bisgaard et al (2005) there is a potential increase in the incidence of chronic post operative pain from 10 – 60% following certain types of surgery which include; thoracotomy, mastectomy, amputation, inguinal hernia repair and cholecystectomy. In the case of cholecystectomy, Bisgaard et al (2005) identify that the risk of developing post operative chronic pain ranges from 10 – 40% and this figure has no bearing on whether the patient undergoes a laparoscopic or traditional laparotomy procedure. Whether the operation is acute or elective also has no bearing on the risk of developing post operative chronic pain. Yet for amputation, thoracotomy, mastectomy and inguinal hernia repair, Perkins and Kehlet (2000) and MaCrae (2001) suggest that the post operative chronic pain has a number of causal associations. These include the level of pre-operative pain, how close the operation is to large nerves as well as the intensity of the acute post operative pain.

The concept of pre-operative pain and anxiety was first identified by Heyward (1975) who hypothesised that a reduction of uncertainty in future events e.g. pre-operative preparation is a viable way of reducing anxiety and thus pain experience in the post-operative period.

The psychological consequences of acute pain are recognised as anxiety and fear of movement and re-injury (Vlaeyen et al, 1995; Vlaeyen and Crombez, 1999; Vlaeyen and Linton, 2000). The contribution of fear and anxiety in the area of pain has been

increasingly acknowledged (Vlaeyen et al, 1995; Carter and Gillies, 1998; Vlaeyen and Crombez, 1999; Vlaeyen and Linton, 2000; Leeuw et al, 2006). Leeuw et al. (2006) also recognise that pain related fear and anxiety are defined as the fear that emerges when pain related stimuli are perceived as the main threat. In the majority of individuals with acute pain, reducing the pain with analgesia can result in the reduction of anxiety (Carter and Gillies, 1998). Vlaeyen et al (1995), Vlaeyen and Crombez (1999) and Vlaeyen and Linton (2000) ground breaking studies recognised and developed models to illustrate the psychological issues around fear of pain but with a focus on back pain. These studies have helped identify fear of work based activities as well as fear of movement, which some individual's view as risking re-injury, are thought to be influential in the development of chronic pain.

Horn and Munafò (1997) remind us that whilst acute pain is generally regarded as the 'normal' manifestation of some physical pathology, the range of syndromes and diseases where the pain is described as acute are vast; by contrast there are narrow ranges of situations where pain does not resolve.

Superficially the only difference between chronic and acute pain is duration (Nielson 2001) but as discussed previously, there is more to both experiences. Unlike acute pain, chronic pain is not a ubiquitous human experience (Kleinman, 1992). Chronic pain is described by Hellström (2001) as a major health problem in society that strongly affects the individual's life situation in psychological, social as well as in biological respects. This is also demonstrated by Hall - Lord et al (1999) who describe chronic pain as a complex health problem which is influenced by psychological, social and existential factors.

LeShan (1964) also, describes chronic pain as being alien and indicates utter senselessness. Whilst, Bullington et al (2005) suggests that for the majority of people chronic pain is often not comprehensible in the same way as acute pain. Chronic pain differs from acute pain in several ways. It is described as persistent and becomes the centre of focus for those experiencing it (McCaffery et al, 2003), it has no biological utility, and it is rarely diagnostic and tends not to respond to medical treatment (Smith and Osborne, 2007). Chronic pain can be divided into two paradigms (Morrison and Bennett, 2006) – *chronic benign pain* in which long term pain can be experienced to a similar degree over time such as lower back pain and *chronic progressive pain* where the pain becomes progressively worse over time as a result of a progressive disease such as rheumatoid arthritis. In addition there are chronic pain conditions that have no identifiable physical cause (Carter and Gillies, 1998; Morrison and Bennett, 2006) such as some types of back pain or fibromyalgia.

With the exception of post operative chronic pain discussed earlier it is evident from the literature that our understanding of whether acute pain progresses to chronic pain remains unclear (Main and Watson, 1999). The process is multifactorial and not fully understood because eventual treatments and interventions for chronic pain are beyond the scope of traditional medicine (Horn and Munafò, 1997). Although there is recognition that there are a number of key processes involved such as social and psychological factors. There is increasing evidence that psychological factors such as the role of *catastrophising* and *fear of movement* are responsible for the transition from acute to chronic pain (Lamé et al, 2005). These psychological aspects are expanded by Ogden (2007) and illustrated in figure 2.4 (page 52). Here Ogden (2007) demonstrates how pain can be viewed not only as psychological but also a social construct. An example of the affects that social construct has on an individual's pain perceptions are based on theories of associative learning (Ogden 2007). This has particular resonance in classical conditioning; where an individual can associate a particular environment with pain. Ogden (2007) cites an example as an individual who associates the dentist with pain due to previous traumatic experience. Therefore pain perception may be enhanced when attending the dentist because of this expectation. This can lead to an increased anxiety which could also increase pain. Although figure 2.4 (page 52) does help to illustrate the psychosocial aspects of pain it does not demonstrate that a number of the factors can also be two way because pain is subjective. There are situations where the results of having chronic pain can further influence and evolve the psychosocial aspects of pain. Additionally Ogden (2007) identifies that figure 2.4 (page 52) represents subjective-affective-cognitive and behavioural processes.

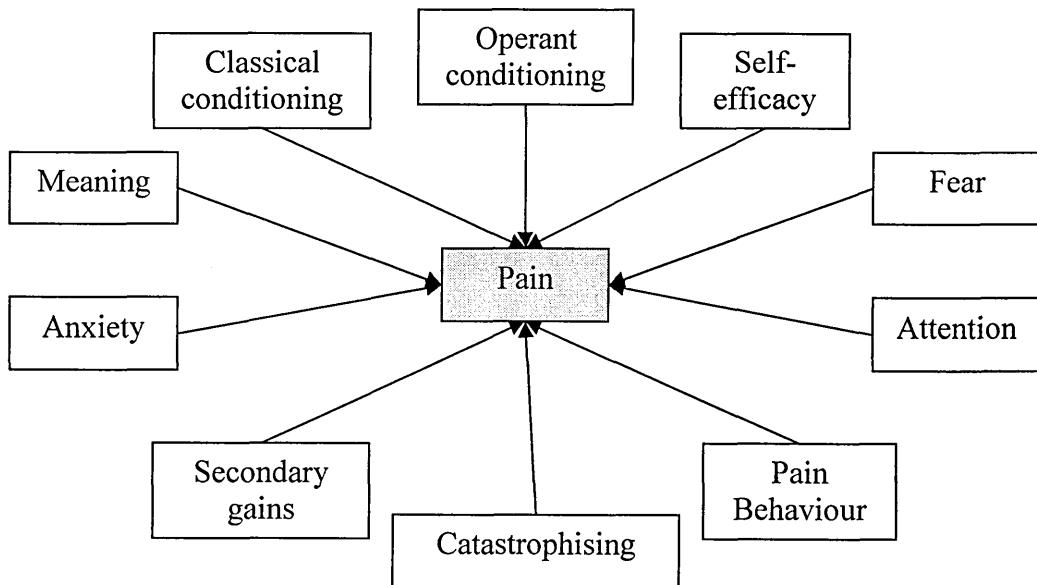


Figure 2.4 - Psychosocial aspects of pain (Ogden 2007, page 276)

2.5.2 Chronic Pain as a Consequence of Chronic Illness

It is reported in the literature (Gold and Roberto, 2000; Fe-Bornstein, 2002, Melding, 2004; Zyczkowska et al., 2007) that in the older age group, chronic pain is believed to be a consequence of chronic illness. The musculoskeletal system is highlighted as the primary cause, chronic conditions cited include; osteoporosis, osteoarthritis and rheumatoid arthritis (Badley and Tennant, 1992, Brochet et al., 1998, Gold and Roberto, 2000 Rustøen at al., 2005). This is reflected in an interview study by Charles and Walters (1998) whereby 75% of the female participants over 50 years had arthritis, compared with 26% of those under 50. Older adults can also be the most affected by other painful illnesses such as Parkinson's disease, poor circulation, inflammatory disease and herpes zoster (Gold and Roberto, 2000).

Summary

In this section of the chapter I have reviewed the literature concerning acute, chronic cancer and non-cancer pain. I have excluded cancer because the pain experienced is not necessarily the dominant symptom. Additionally as I have reported those with chronic non-cancer pain report the experience for longer which impacts on reporting poor physical, social and emotional functioning. One or more of these aspects of chronic non-cancer pain may be the motivational factor for joining a support group.

2.6 Pain Theories

The theory of pain that was dominant in the 20th century was proposed by Descartes in the 17th Century (Melzack, 1996). Descartes regarded pain as a response to a painful stimulus. He described a direct pathway from the source of the pain to an area of the brain that detected the painful sensation. In 1895 Von Frey developed the specificity theory of pain which reflected the very simple stimulus-response model (Ogden, 2007). In 1920 Goldschneider developed the pattern theory suggesting that the nerve pulse determined the degree of pain (Ogden, 2007). The combinations of all these led to a theory of pain (Table 2.3).

Tissue damage causes the sensation of pain
Psychology in this model of pain is used but only as a consequence of pain (anxiety, fear depression) and not a causal influence.
Pain is an automatic response to an external stimulus. There is no place for interpretation or moderation
The pain sensation has a single cause
Pain was either psychogenic (in the patient's mind) or organic pain (real pain e.g. where a clear injury is present)

Table 2.3 - Early pain theories (Ogden, 2007)

These theories of pain determined the facts as they were known right up until the middle of the 20th Century (Melzack, 1996) even determining therapy; an example is that there were attempts to treat severe chronic pain by a variety of neurosurgical lesions. The theory suggested that injury activates specific pain receptors and fibres that in turn, project pain impulses through a spinal pathway to a pain centre in the brain (Figure 2.5).

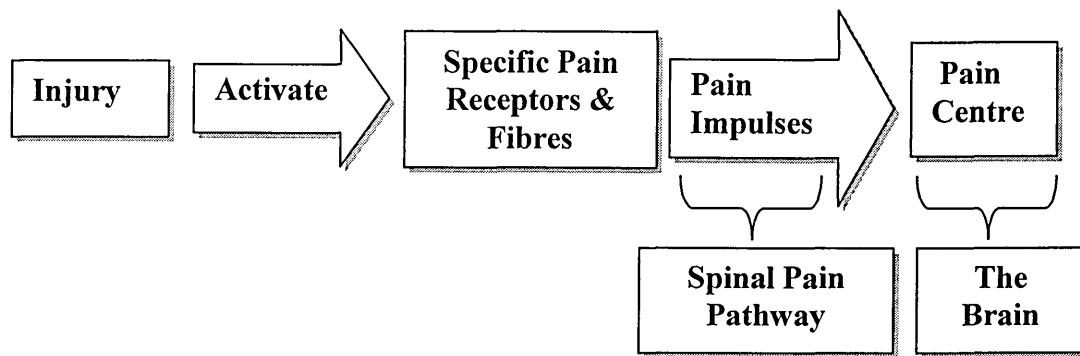


Figure 2.5 - Early theory of pain based in Descartes (Melzack, 1996)

The theory presented in figure 2.5 shows that the psychological experiences of pain is none existent which influenced treatment for chronic pain. An example of this is the treatment of people presenting with lower back pain without signs of organic disease were labelled as psychologically disturbed and regularly sent to psychiatrists (Melzack, 1996). This concept of chronic pain is now recognised as failing to help people experiencing chronic pain (Samwel et al, 2006). Chronic pain can have multiple consequences for an individual's daily life such as limiting daily functioning which can cause heightened levels of depression (Samwel et al, 2006). The biomedical model has *no room* for psychological contributions to pain such as attention, past experience and the meaning of the situation (Melzack, 1996).

Additionally Samwel et al (2006) posits that biomedical factors have limited influence on pain level, functional disability and depression whereas there is strong evidence that psychological factors can affect outcomes over time in those experiencing chronic pain (Samwel et al, 2006)

2.6.1 The Gate Control Theory (GCT)

The Gate Control Theory (GCT) (Melzack and Wall, 1965) takes both the psychology and physiology associated with pain. The theory uses the analogy of an opening and closing gate to explain the pain experience. Table 2.4 below illustrates the fundamental differences of the GCT to previous pain models.

Pain as a perception – that pain is a perception and an experience rather than a sensation. This reflects the role of the individual in the pain experience.
The individual as active, not passive – the individual does not respond passively to painful stimuli but actively interprets and appraises the painful stimuli
The role of individual variability – This aspect is central to the GCT – Variation in pain perception is understood in terms of the degree of opening and closing of the gate
The role of multiple causes – GCT recognises that there are multiple factors involved in pain perception – not just a singular physical cause.
Is pain ever organic? GCT describes most pain as a combination of physical and psychological.
Pain as Dualism – the GCT attempts to depart from the traditional dualistic models of the body and mind – its suggests there is an interaction between the two

Table 2.4 - How the Gate Control Theory differed from previous pain models

(Ogden, 2007)

In table 2.4 I presented the ways that the GCT differed fundamentally to previous models. One of the ways that it differs is recognition that pain perception is understood in terms of the degree of opening and closing of the gate. According to Melzack and Wall (1965) and Melzack et al (1982) the more a gate is opened, the greater the perception of pain.

They suggest several factors which can open the gate including; *physical* such as injury or activation of the large fibres (figure 2.6), *emotional* factors such as anxiety, stress and depression, *behavioural* factors such as focusing on the pain. In contrast closing the gate reduces the pain perception (Melzack and Wall, 1965; Melzack et al, 1982).

The same factors that were reported as opening the gate can also close it. Physical factors in this case include medication and stimulation of the small fibres (figure 2.6). Emotional factors such as happiness, optimism or relaxation. Behavioural factors include concentration and distraction.

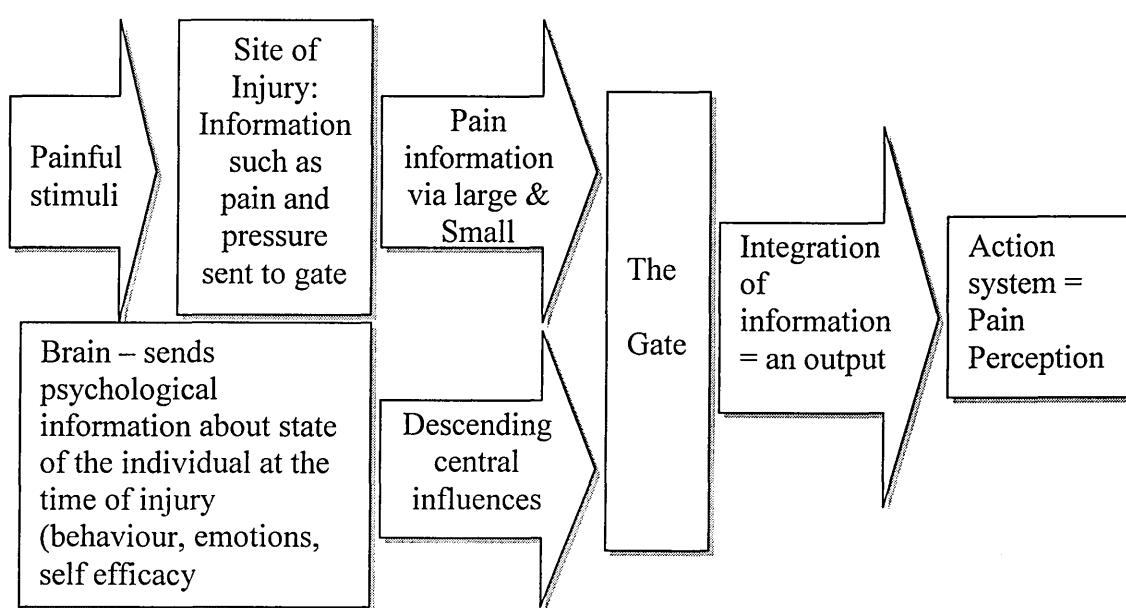


Figure 2.6 - The Gate Control Theory (GCT) (Melzack and Wall, 1965)

The publication of the Gate Control Theory by Melzack and Wall (1965) did not begin to make an impact on the medical approach to managing pain until the 1970s (Melzack, 1996). This opened up new approaches to the management of pain, which rather than viewing psychological factors as a reaction to the sensation it was now seen as an integral part of pain processing (Melzack, 1996).

In addition cutting nerve pathways was gradually replaced with other methods to modulate input. These included the introduction of physiotherapists who use numerous modulation techniques into the management of pain. Transcutaneous Electrical Nerve Stimulation (TENS) were also used for the treatment of both acute and chronic pain.

There are recognised issues within the literature on the use of the GCT on individuals who are paraplegic or are experiencing phantom limb phenomena (Melzack, 1996) and discussed in the neuromatrix theory later in this section. In the case of paraplegia, Melzack (1996) suggests that peripheral and spinal processes are an important part of pain.

2.6.2 Neuromatrix Theory of Pain

As I have pointed out in the previous section one of the issues with GCT is the explanation for phantom limb phenomena. Developed by Melzack (1999) the neuromatrix model has three key assumptions which are shown in table 2.5 (page 58). Melzack (1999) suggests that the body is made up of a large widespread network of neurons. These neurons link the thalamus, cortex and limbic systems in the brain. The theory suggests that related information about the pain such as physical elements of the injury, emotional reaction etc., combine to form a *neurosignature* which is further described as network of information about the nature and emotional reaction to painful stimuli (Morrison and Bennett, 2006). The neurosignature have two components 1) the body self matrix which processes and integrates incoming sensory and emotional information and 2) the action neuromatrix which develops behavioural responses as a reaction the networks.

The same neural processes that are involved in pain perception in the intact body are involved in pain perceptions in the phantom limb – Melzack (1999) suggests these processes are pre-wired to assume that the limbs can move. In the case of amputation the body will still send signals to try and move them. When they do not move to these signals stronger more frequent messages could be sent to the muscles and these are perceived as pain (Morrison and Bennett, 2006).

All qualities that we normally feel from the body, including pain, can be felt in the absence of inputs from the body.

The body is perceived as a unity and is identified as the self, distinct from other people and the surrounding world.

Table 2.5 -The three key assumptions of the neuromatrix model

Derbyshire (2000) posits that the central response to noxious stimuli is evidently broad and complex and this has been captured by Melzack's neuromatrix as well as the biopsychosocial model which will be discussed later in this section. However Derbyshire (2000) is not convinced that the neuromatrix is a theory with which to understand the neuropsychology of pain because the explanations of the processes are critically absent. Although Derbyshire (2000) acknowledges that findings from functional images have been extremely useful in expanding knowledge of what a brain does when it is faced with noxious stimulus. What is lacking is an understanding of how certain brain regions perform functions and how these may be dysfunctional in some people with chronic pain (Derbyshire, 2000). Finally Derbyshire (2000) concludes that advances in our understanding of pain and its mediations by the brain will occur when we are able to step beyond the general understanding that is offered by the neuromatrix or we develop another model or theory to explain the baffling array of activation patterns in individuals who are experiencing pain.

2.6.3 Biopsychosocial Model of Chronic Pain

The biopsychosocial model focuses on both disease and illness, with illness being viewed as the complex interaction of biological, psychological and social factors (Gatchel et al, 2007). This context is further explained by Gatchel et al (2007) through the following definitions of how disease and illness differ. Disease is an objective biological event involving the disruption of specific body structures or organ systems caused by anatomical, pathological and physiological changes (Gatchel et al, 2007). This is in contrast to illness which refers to a subjective experience or self attribution that a disease is present. In this context illness refers to how a sick person and members of their family respond to symptoms of disability (Gatchel et al, 2007).

As previously identified the traditional biomedical model of pain is insufficient in explaining the complexity of the pain experience (Gatchel et al, 2007), Vlaeyen and Crombez (1999) recognised that this model limits pain treatment as it can only consist of two possible acts; localisation of the underlying pathology and removal of the pathology with the appropriate remedy or cure. Vlaeyen and Crombez (1999) further explain that the biomedical approach is moot because tissue damage is not necessarily a condition of pain as it can also be considered as an emotional experience. Melzack and Wall's (1965) Gate Control Theory (GCT), presented on page 55 of this chapter, has recognised and dealt with some of the short-comings of the biomedical model such as psychological issues. These issues have been recognised by the International Association for the Study of Pain (1986, 1992) who further defines pain as;

'An emotional experience associated with actual or potential tissue damage, or described in terms of such damage.' (Pg. 210)

Gatchel et al (2007) recognise the importance that emotional disorders such as anxiety, depression and anger as well as maladaptive cognition (such as catastrophising and poor coping skills), functional deficit and physical deconditioning. These variables are interdependent, meaning that one cannot be treated to the exclusion of the others (Gatchel et al, 2007). According to Lamè et al, (2005) the prevailing model of chronic pain is now based on a biopsychosocial approach (figure 2.7, page 61), where psychological distress can lead to depression, pain related fear and illness behaviours such as catastrophising play the prominent role. Gatchel et al (2007) posit that the emergence of the biopsychosocial model of chronic pain as leading to the development of a more complete approach to management including multi-disciplinary pain teams. In the UK the experience of people with chronic pain is still very variable (DoH, 2001). In some circumstances the health professional will discuss the nature of the treatment and care and a plan for management is agreed (DoH, 2001). However in some circumstances there is still a focus on the technical issues of the illness with inadequate attention paid to the social and emotional consequences of chronic pain (DoH, 2001). This variable approach impacts on the lives of older adults according to Kumar and Allcock (2008) who recognise that the provision of specialist pain services vary greatly across the UK and older people are rarely referred and treated under programmes specifically addressing issues of pain.

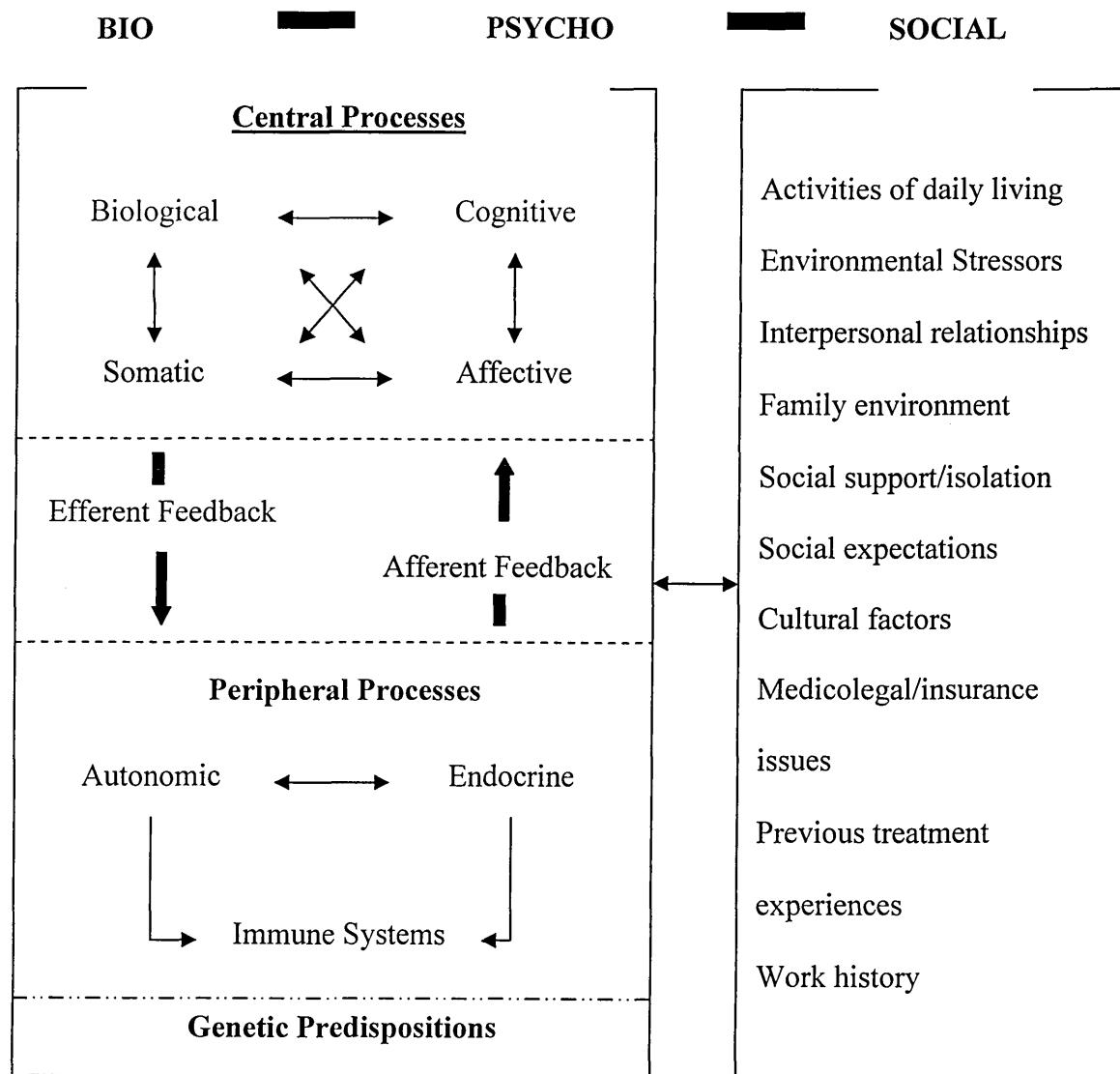


Figure 2.7 - The conceptual model of the biopsychosocial interactive (Gatchel, 2004)

Summary

The theories and models have helped our understanding of chronic pain and consequently how to manage it more effectively. The general dissatisfaction of the biomedical approach in explaining why chronic pain affects individuals in different ways is confirmation of the subjectivity of the chronic pain experience. The gate control theory has helped to establish that there is psychological involvement in the pain experience but it did not explain phantom limb pain. The neuromatrix theory is a relatively new development in our understanding of pain and further work will help us to understand more aspects of the experience. The biopsychosocial model views illness and disease such as pain, as the result of a dynamic interaction among physiologic, psychological and social factors. These perpetuate or can even worsen clinical presentations and each may have an influence on the motivation of older adults to join a support group.

Although there is the possibility that older adults may be motivated to attend support groups in response to a combination of dissatisfaction with the formal healthcare. It is recognised in the literature that in the United Kingdom older adults are not being referred to pain management groups despite being recognised as the largest cohort experiencing it.

2.7 Social Aspects of Pain

The potentials for loneliness disproportionately affect older adults due to their shrinking social networks (Bondevick and Skogstad, 1998; Hawton and Harriss, 2006; Raue et al, 2007). Older adults often identify their inclusion in society as important to their quality of life as well as their independence (Hollywood 2007). Many older people in the report by Hollywood (2007) identified good relationships with family and friends and to have a role in society, to feel useful and to be treated with respect as salient issues for their quality of life. There are a number of risk factors that may lead to social exclusion (Killeen, 1999; Hollywood, 2007) including bereavement and poor health. In addition Torres and Hammarström (2006) identifies that advanced old age often comes hand in hand with not only a variety of health problems but also situational constraints, along with increased dependency on others and a gradual narrowing of future perspectives.

Weiss (1973) specifies that loneliness is conceptually comprised of two primary dimensions; emotional and social isolation. Emotional isolation refers to a lack of others to whom the individual can be emotionally attached (Weiss, 1973; Pettigrew and Roberts, 2008). Emotional isolation prevents the experience of social bonding that is instinctively desired. This dimension of isolation is recognised by Weiss (1973) and Pettigrew and Roberts (2008) as a negative experience. Social isolation occurs when an acceptable social network is lacking (Weiss, 1973; Pettigrew and Roberts, 2008).

In contrast to emotional isolation, social isolation is not always perceived as a negative outcome because time spent alone can be perceived as enjoyable and productive (Weiss, 1973; Pettigrew and Roberts, 2008). However the experience of loneliness includes both emotional and social isolation and is therefore unpleasant by definition (Killeen 1998; Pettigrew and Roberts, 2008). According to Pettigrew and Roberts (2008) loneliness has been identified as a primary mental health problem that affects older adults. There are numerous studies (Alpass and Neville, 2003; Cacioppo et al, 2006) that have reported a link between loneliness and depression amongst older adults.

There is a suggestion that research should focus on identifying ways to impede the loneliness-depression pathway (Pettigrew and Roberts, 2008). There is also evidence that there is a bidirectional relationship with depression also being reported as leading to loneliness due in part to an inability to maintain social networks (Tiikkainen and Heikkinen, 2005; Pettigrew and Roberts, 2008) . The experience of loneliness is correlated with a variety of other psychological and physical conditions including actual and perceived ill health, dietary inadequacies, excessive alcohol consumption, depression, personality disorder and suicide (Pettigrew and Roberts, 2008). Tijhuis et al (1999) has suggested that chronic illnesses such as arthritis results in higher levels of dependence are particularly problematic. This would suggest that older adults may not attend support groups predominately to obtain social contacts.

Past research has focused on the incidence and causes of loneliness and possible methods of alleviating the condition (Pettigrew and Roberts, 2008). However current thinking suggests that strategies that empower the individual to improve their self efficacy may be beneficial (Hollywood, 2007; Ord, 2008; Pettigrew and Roberts, 2008). According to Pettigrew and Roberts (2008) many of these strategies have yet to be implemented and those that have been implemented need to be adequately evaluated.

In a qualitative study by Pettigrew and Roberts (2008) nineteen older adults aged 65 years plus participated in semi-structured interview focusing on a typical day in the life of the individual. Loneliness was not raised as a specific subject of discussion until it was felt by the interviewer that rapport had been established. Despite this loneliness almost always emerged as a topic of discussion prior to its formal introduction. The fact that participants knew that they had been recruited into a study on loneliness probably had strong bearing on this. The results of the study are presented in themes including, attitudes to loneliness, interacting with one another, eating and drinking rituals, reading and gardening. Pettigrew and Roberts (2008) report that the majority of the participants perceived themselves to be lonely at least some of the time and some considered themselves to be chronically lonely. The participants believed that loneliness was an inevitable part of the ageing process due to increase social isolation that has resulted from health, shrinkage of existing social networks due to death and family members being to be busy to spend time with them.

The participants identified that a lack of human contact and satisfying emotional relationships with others was a salient issue regarding loneliness. Those who described their loneliness as chronic considered that any form of human interaction was favourable. This was apparent in their reporting of the enjoyment they received from interactions with caregivers who visited them to provide meals and housekeeping services. The most meaningful human interactions were reported as those involving loved ones, especially children and grandchildren.

Female participants in particular expressed happiness and satisfaction in which they stay in contact with family members. They expressed a desire to be involved in the extended family and to be of use to loved ones, this manifested itself in performing tasks for their families the most common of these being childcare. Those who lacked access to family members described feelings of being bereft of meaningful social contact. Some of the respondents reported that keeping pets made positive contributions to alleviating the sense of social isolation and in some circumstances helped to provide regular exercise. The preparation and consumption of food were consistent elements of how the participants spent their time, preserve their health and maintain interactions with family and friends. It was reported that meals, snacks and drinks offer a reason for coming together with friends and family.

Most of the study participants identified themselves as avid readers. They suggested that they found books almost to be self medicating as a way of alleviating symptoms of loneliness because they offered a window into the world. Male respondents were more likely to read newspapers because of this link to the external world.

Gardening was also identified as another form of loneliness prevention. Gardening is also reported as having a positive effect on loneliness in older adults and in the disabled in a report by Ord (2008). Primarily the reason that the participants felt that gardening provided them with a sense of functionality and purpose. Even in those who could no longer participate in this particular activity enjoyed looking at their garden through a window and this resulted in reports of a long-lasting sense of satisfaction.

Friends were also valued but interestingly it was reported that there was reluctance among some of the participants to establish new friendships with those their age. This was justified by some because of a dislike of the interaction styles especially their verbosity and complaining behaviours. Pettigrew and Roberts (2008) posit that this could help to explain the inability of some friendship enrichment programmes to reduce loneliness amongst older adults.

There were some study participants who reported actively seeking the company of other people on a regular basis but the majority seemed to prefer to wait for others to come to them, rather than taking on the role of social instigator. Pettigrew and Roberts (2008) offer a possible solution to this and report on an intervention that is currently being implemented in Australia. They suggest that older adults should be made aware of the socialising opportunities that are available in small and large groups in their particular location. The uniqueness of this particular intervention is that there is a deliberate intergenerational mix. The nature of some of the groups involves an amount of volunteering which has the potential to be another loneliness prevention strategy.

Older adults who are able to volunteer could benefit by becoming more physically, mentally and socially active which could contribute to improved health. This has bearing on this current study as support groups with a link to national charitable organisations may require a certain amount of volunteering such as supermarket and street collections as well as committee membership.

2.7.1 Reporting Chronic Pain

In the past chronic pain and older adults had not received serious consideration, Gagliese and Melzack (1997) believe that this was due in part to widely held beliefs that older adults were less sensitive to pain, and that pain is a normal and expected consequence of ageing. The problem is, that prevailing concepts regarding disease and illness in society has profound effects on individual reactions (Bury and Wood 1979). Pain that interferes with normal life should not be viewed as a normal part of the ageing process (Sofaer et al 2005; Kumar and Allcock 2008) but older adults may regard it this way.

Acceptance that chronic pain is a natural occurrence of the ageing process may be the primary deterrent for *help seeking behaviour* in older adults (Morgan et al. 1997; Zyczkowska 2007). There are multiple factors that can contribute to this. Fear is identified by Melding (2004) because some older people are reluctant to report pain symptoms to their carers, partners or medical professionals due to concerns that pain represents something more catastrophic or life threatening. There is also a suggestion that the side effects or addictive nature of analgesics is also a deterrent (Benshoff and Harrawood, 2003; Melding, 2004; Kumar and Allcock 2008).

This is the result of a lack of understanding on their part combined with the attitudes of medical professionals (Morgan et al, 1997; Melding, 2004; Kumar and Allcock, 2008).

It is also possible that older adults may chose to avoid diagnostic conformation in response to the personal concerns that they hold that the symptoms are perceived as a decline due to ageing (Morgan et al 1997). In addition Kumar and Allcock (2008) report that many older adults in the United Kingdom feel let down by the health service, this results in the low expectations of both the system and the health professionals. This view of the formal healthcare system may contribute to a decision by older adults to seek help from less formal organisations such as support groups.

Attitudes to what constitutes *normal* symptoms can be an influential factor in help seeking behaviours. An example of this was seen in the Morgan et al (1997) interview study with older adults. The study was conducted to ascertain the participants' beliefs and perceptions about common symptoms. The intention was to identify what action they would take in response to each individual symptom. The result of the study demonstrated that concrete symptoms which may indicate psychiatric disorders, such as low mood, disturbed sleep, and forgetfulness, were *common* but were generally not considered to represent disease and seemed not to be thought of as symptoms that required a medical opinion. This *self imposed* prevention of medical help seeking by older adults could be a motivational factor in the decision to participate in a support group.

2.7.2 Pain Descriptions

All pain is subjective and cannot be measured in the same way as the blood pressure or a pulse. Baszanger (1992) refers to pain as a person's private experience, to which no one else has direct access, Scarry (1985 pg 4) explains that;

"Whatever pain achieves, it achieves in part through its unsharability, and ensures this unsharability through its resistance to language".

Language and communication are important issues for those experiencing chronic pain. Scarry (1985) describes physical pain as not only resisting language but actively destroying it. Smith (1998) explains that the word pain can be used equally to refer to mental and emotional distress or suffering. Indeed the literature highlights that the language and communication of chronic pain can itself be problematic. Focusing on medical management of pain, Baszanger (1992) describes problems regarding defining a credible and authoritative definition of what chronic pain *is*, could then delimit and disorganise practice.

If pain is a private experience then it is difficult to describe, the word pain is inadequate to truly communicate to those who are not experiencing it. There are multiple descriptors that people use when describing their pain such as *ache* and *stiffness*. Those individuals with chronic pain use descriptors such as stabbing, throbbing, dull and sharp as well temperatures like burning, hot, frozen or cold (Scarry, 1985). This has led to the development of the McGill pain questionnaire (Melzack & Torgerson 1971) which aims to quantify the qualitative aspects of pain. Pain has religious metaphors such as *experiencing hell* or *being punished* or violent metaphors such as *murder* or *torture* (Scarry 1985; Delvecchio – Good et al 1992; Frank 1995; Carter and Gillies 1998; Paulson et al 2001)

2.7.3 Pain Perceptions

The literature links pain perception to pain outcome and what is predominant is that the perception of those experiencing chronic pain are linked to coping and chronic pain outcome. How the individual perceives pain can be dependent upon a number of factors including what they have learned about pain from previous experience. Fordyce (1976) describes two factors that share responsibility for people's perception of pain; one is *classical conditioning*, which was described earlier on page 51 (Ogden 2007). Young - Casey et al (2008) describe past traumas as 'hard-wiring' those affected to experience more intense pain in similar circumstances or injury. The other factor is described as *operant conditioning* (Fordyce 1976) whereby individuals respond to pain by demonstrating pain behaviours such as resting, grimacing, limping or being absent from work. This behaviour maybe reinforced by others with sympathy, attention and time off work, these positive reinforcements may also increase pain perceptions.

2.7.4 Attitudes of others

An aspect of the psychosocial adjustment to chronic pain is the perception of others through being understood and recognised for their physical and psychological suffering. Herbette and Rimé (2004) report that because pain is invisible the individual can feel discredited by their lack of ability to demonstrate and communicate their pain and this disbelief or minimisation of their pain can result in them questioning the integrity of their experience and possibly discredit their own identity. Scarry (1985, p7) states *the doubt of others amplifies the suffering of those already in pain.*

Psychology also has consequences regarding stigma as Glenton's (2003) Norwegian back pain study demonstrated; his respondents believed that when illness is seen as psychological, questions can be raised with regards to personal responsibility. Psychological explanations for their pain appeared to divide those that participated in the study leaving some unwilling to accept the explanation for the pain while others did complain of psychological problems which they attributed to their long-term pain. Fear of stigma attached to mental illness as well as fear that a psychological diagnosis would potentially lead to delegitimation of the physical pain experience led to some participants hiding their problems. Psychosocial and psychiatric diagnosis came from health professionals after clinical tests and examinations continued to show nothing. The study concluded that to receive a psychosocial or psychiatric diagnosis for the participants was a source of despair and frustration.

The participants in Glenton's (2003) study also expressed fears that those in their social surroundings would question the reality of their pain and suspect them of being malingeringers, hypochondriacs or even mentally ill. This was seen as problematic particularly in the work environment, with friends and neighbours, as respondents felt that a lack of any visible disability may have the effect of disbelief and delegitimation of the systemic disconfirmation of one's illness perception (Wade, 1992) amongst their peers in the same way that disbelief was displayed by health professionals.

This aspect of chronic pain may be a motivational factor in joining a support group as described in the work by Cohen and Janicki-Deverts (2007). Those with a diverse social network with more types of relationships such as being married, having close family members, friends, neighbours and belonging to political or social groups are reported to live longer (Cohen and Janicki-Deverts, 2007). Additionally those with more diverse social networks are also associated with better prognoses among those with chronic life threatening illnesses, in this case cardiovascular disease (Cohen and Janicki-Deverts, 2007). There is also evidence that those with perceived social support (people reporting that others will provide them with aid when they are in need) are protected from the pathogenic effects of life stress (Cohen and Pressman, 2004).

Cohen and Janicki-Deverts (2007) propose that the association between social integration and health maybe driven by two processes: one associated with being isolated versus having minimum contact with between one and three other people, and the other associated with incremental increases in network diversity. Cohen and Janicki-Deverts (2007) also recognise that the role of social environments could be especially important for older adults who experience major social transactions such as retirement, bereavement and inability to participate in social activities because of disability or lack of mobility. Relevant to this current study Cohen and Janicki-Deverts (2007) suggest there are health benefits in engineering social environments, encouraging people to maintain good health and address bad health, additionally this has the potential to control health care costs. This aspect of social support is reported in the UK governments National Service Framework for older people (DoH, 2001).

2.7.5 Learned Helplessness

The theory of learned helplessness and the link with depression was first described in a model by Abramson et al (1979). Helplessness is characterised by negative outcome expectancies and for those with chronic pain the risk of helplessness is increased by a learning history of unsuccessful coping with the pain (Samwel et al, 2006). The results of unsuccessful coping are characterised by negative outcome expectancies for those experiencing pain and this could contribute to avoidance behaviours and therefore may result in chronic pain, disability and depression (Samwel et al, 2006).

Catastrophising (page 79) can lead to feelings of helplessness (Edwards et al, 2006).

As I will report later on page 85 there is a direct link with pain and depression (American Psychiatry Association, 2000), Baron and Kenny (1986) posit that helplessness as a mediator can cause an indirect link to depression associated with pain (figure 2.8).

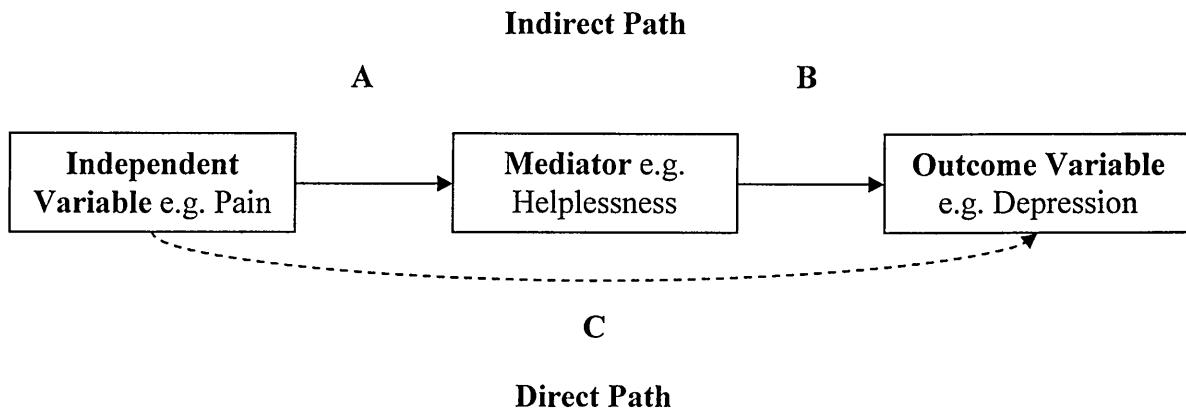


Figure 2.8 conditions for mediation (Baron and Kenny, 1986)

Figure 2.8 (page 74) suggests that there is more than one causal path that feeds into the outcome variable, in this case depression. Path C shows the direct impact of the independent variable. Path B shows the impact of the mediator in this case helplessness. Path A shows that there is also a path from the independent variable (pain) to the mediator (helplessness).

The potential role of a support group could help limit the amount of helplessness which has resulted from a failed history of coping. This is perhaps due to collective wisdom through shared information amongst members of the group which could contribute to a more successful self management approach.

Summary

The social construct of chronic pain in older adults identifies a number of issues which may motivate help seeking in support groups. The literature has identified that loneliness is disproportionate in older adults because of a shrinking natural social support network due to death and decreasing mobility. The ideals for older adults identified in the literature are for positive engagement with family and friends, to feel useful and to be respected. Loneliness has been reported as having an impact on emotional and social support and this may be a motivational factor for help seeking in support groups. However there is also the suggestion that older adults do not want to be grouped together with others from this age cohort, they report that complaining behaviours are the salient reason for this. This may impact on motivation to join a support group because preconceived ideas of purpose and who would be attending may prevent older adults from becoming members.

The literature recognises that there are issues in reporting chronic pain in this cohort, pain appears to be negatively constructed as a normal outcome of the ageing process. There is also evidence to suggest that this perception maybe bi-lateral in that healthcare professionals may also view chronic pain as normal in older adults. This chapter has recognised that pain is subjective and this has influenced how the semi-structured interview is constructed and words like pain may be interchanged with ache for example.

2.8 Psychology of Pain

2.8.1 Stoicism, Cautiousness and Chronic Pain

The results of a study by Cook et al (2006) found that older adults (aged 55 and older) have lower levels of pain related fear than middle aged patients, the most frequently represented group in pain clinics. Yet as Kumar and Allcock (2008) have indicated older adults are the cohort that is less likely to be referred to pain clinics. Cook et al (2006) also found in contrast to Turk et al (1995) that there was weaker association between depression and pain severity amongst older adults. From the findings there is evidence to confirm the conclusions of work by both Cook and Chastain (2001) and Yong et al. (2001) that there are more stoic beliefs and reactions to pain amongst community based older adults than in their younger counterparts.

The personality of the older adult, with particular reference to the effect that stoicism has on pain reporting is not discussed in detail within the literature. Yong (2006) identifies that there is a lack of literature and empirical evidence regarding the relationship that *stoicism* and *cautiousness* have in the reporting of chronic pain amongst older adults. Stoicism and cautiousness are polar opposites and Yong (2006) believes that they have a bearing on the underreporting of pain symptoms and describes them as an actual barrier to pain management. He identifies that previous research has focused primarily on the relationship of cognitive factors and self rated levels of pain impact and suffering of the individual experiencing chronic pain. Attitudes of stoicism and cautiousness may have a role in influencing levels of adjustment to chronic pain. This was one of the findings of the study by Zyczkowska et al (2007); here they conclude that older adults may report less pain because they have increased stoicism.

In contrast Yong (2006) also suggests that the persistence and uncertain nature of chronic pain can mean that cautious attitudes are likely to be relevant. He gives an example that chronic pain patients may underreport pain not because of stoicism but because they are more cautious about reporting it as highlighted by Morgan et al (1997) and discussed on page 76. The reason for this cautious reporting could arise from the fact that chronic pain often has an uncertain aetiology. Therefore those in chronic pain could be doubtful about their pain experience. Beese et al (1999) suggests that the *mysterious* nature of pain can influence when and to whom pain is communicated.

Morley et al. (2000) add that cautious reluctance to report pain stems from the fear of not being believed given the *chronicity* of the pain. Also, of particular value to older adults Morley et al (2000) reports that amongst this cohort there is the desire to be viewed as a *good* patient through not being a burden to others and the need to maintain a relationship with significant others such as family and friends. This belief may change with other ageing cohorts due to their approaches to healthcare professionals as well as changes to naturally occurring support networks (Cohen and Janicki-Deverts, 2007). The results of the study by Yong (2006) demonstrated that age was significantly related to lower levels of self rated pain, depressive symptoms, anxiety and functional interferences.

In contrast Zyczkowska et al (2007) reported that there was no significant variance between age and pain severity. Although the conclusions in both the Zyczkowska et al (2007) and the Yong (2006) study were that stoicism does have an impact on symptom reporting and adjustment to chronic pain. When stoicism is present it can result in the underreporting of pain symptoms. However Yong (2006) found that the relationship between cautiousness and stoicism in reporting pain symptoms was not supported. This suggests that any under-reporting of pain symptoms were unlikely to be due to the individual doubting their pain or reluctance in labelling something painful. A clinical implication of this is that patients with a *stoic* presence could pose a significant barrier to adequate pain management. Yong (2006) recommends therefore that stoicism is routinely assessed in the pain clinic setting. The findings of the Yong (2006) and Zyczkowska et al (2007) studies suggest that the experience of chronic pain is not the same for younger and older adults.

The lower reporting of pain severity commonly observed in older adults could also be due to cautiousness (Yong 2006) and not necessarily because of stoicism. To further clarify Yong (2006) suggests that pain may be underreported not because the individual is stoic but because they are more cautious about reporting pain.

2.8.2 Catastrophising

According to Sullivan et al (2000) catastrophising has been broadly conceived as an exaggerated negative ‘mental set’ brought to bear by actual or anticipated pain experience. In contrast Edwards et al (2006) posits that catastrophising is present but stable in healthy people as well as people experiencing pain. Catastrophising has adverse outcomes on chronic pain including an increase in pain severity, sensitivity, depressive symptoms (low mood) and disability (Edwards et al, 2006). Measurements of catastrophic thinking have been performed on those experiencing acute pain and has been found to be present some weeks later when retested and the person is ‘pain-free’ (Edwards et al, 2006). This would suggest that catastrophic thinking is hardwired within an individual and Edwards et al (2006) recommends that this is an important target for investigation and intervention.

Keefe et al (2000) describe catastrophising as involving three components: 1) rumination – which is a focus on threatening information both internal and external, e.g. ‘I can feel my neck click whenever I move.’ 2) Magnification or overestimating the extent of the threat, an example would be ‘The bones are crumbling and I will become paralysed.’ and 3) helplessness or underestimating personal and broader resources that might mitigate the danger and disastrous consequences e.g. ‘nobody understands how to fix this problem and I just can’t bear anymore pain.’

Catastrophising has an impact on the cognitive coping strategies of an individual; there is also a debate as to whether catastrophising is a cause or consequence of pain (Edward et al, 2006) and there is further possible associations with catastrophising and pain outcomes (figure 2.9).

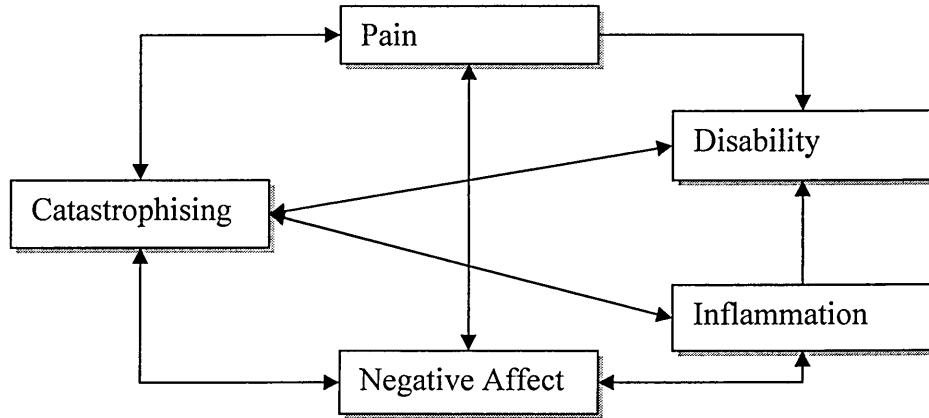


Figure 2.9 The putative associations of catastrophising with pain outcomes

(Edwards et al, 2006)

Although the study by Edwards et al (2006) focuses on individuals with arthritis, fibromyalgia and other rheumatic diseases there are elements that have a relevance to all aspects of chronic pain experience such as the links between negative affect and catastrophising. Edwards et al (2006) hypothesises that catastrophising interferes with pain coping and also beneficial health behaviours, increases attention to pain, amplifies pain processing in the central nervous system and has a maladaptive impact on the social environment.

The maladaptive impact on the individuals' social environment has particular relevance to this current study. An example of this is that high levels of catastrophising are associated with greater perceived stress and a reduction in non-pain related social support within existing social networks. Therefore an individual seeks a more solicitous response to pain and this can lead to a reduction in the general availability of support probably due to the enhancement of distress in others (Edwards et al, 2006).

The literature documents that pain catastrophising is related to high pain reports and difficulties in redirecting attention away from the pain (Crombez et al, 1998a). Catastrophic thinking can also increase distress (Sullivan et al, 2006) which in turn leads to increases in pain by reducing pain tolerance and triggering sympathetic arousal (Ciccone and Grzesiak, 1984). The study by Edwards et al (2006) investigated the relationship between catastrophising and pain in arthritis, fibromyalgia and other rheumatic diseases. The age range of the participants was not reported. The study suggests that those who experience catastrophising are perceived to be coping less well with pain (Edwards et al, 2006). They also suggests that those who experiencing catastrophising are increasingly likely to seek social support, this has relevance to this current study suggesting that catastrophic thinking could be a motivating factor to support group attendance. Chapter 3 will discuss motivating factors for help seeking in support groups in more detail.

Figure 2.9, page 80 presented the cyclical nature of catastrophic thinking, this aspect of chronic pain emphasises the importance of a multidisciplinary approach to pain management (Edwards et al, 2006). There is evidence that self reporting of catastrophising often decreases after the individual receives multidisciplinary approach to pain management as well as cognitive behavioural therapy (CBT). This approach to pain management reduces catastrophising even if it has been experienced for a number of years (Edwards et al, 2006).

2.8.3 Fear Avoidance

According to Samwel et al (2007) both fear of pain and avoidance behaviour are reinforced by a person's experience of pain limitation during the acute phase. This aspect of chronic pain has been recognised as functional disability (Lethem et al 1983; Vlaeyen and Linton 2000). In later work this fear avoidance model has been validated by Linton et al (2000), Fritz et al (2001) and Swinkels – Meewisse (2006). The model states that although fear avoidance can begin in the acute phase during the chronic phase it can be further magnified.

2.8.4 Anxiety

Anxiety is often identified as a correlate of chronic pain (Tan et al, 2008) as well as a link with disability (Lee and Park, 2008, Tan et al, 2008 ;). The DSM- IV-TR (American Psychiatry Society, 2000) recognises that long-term medical conditions such as chronic pain, associated anxiety disorders in this context can include a generalised anxiety, with or without panic attacks or with or without obsessive compulsive disorder. Additionally anxiety can also be present as an adjustment disorder following diagnosis or realisation that the chronic pain experienced will not be cured.

There is also a link between anxiety and depression in adjustment disorders (American Psychiatry Society, 2000), although both depression and anxiety can be present independently. The American Psychiatric Society (2000) also suggest that stress is a marked symptom of anxiety and this could be related to difficulty in sleeping, irritability, poor concentration, hypervigilance, exaggerated startle response and motor restlessness.

Prior to recent studies, there was paucity in the literature regarding chronic pain and anxiety which is recognised by McWilliams et al (2003). They believe that relative to depression, anxiety disorders have received little attention in chronic pain literature. McWilliams et al. (2003) identify that the prevalence of depression in chronic pain is higher than any of the anxiety disorders; therefore the emphasis in the literature is understandable. However the findings of their study suggest that anxiety warrants further research. The association of chronic pain and anxiety disorders such as post traumatic stress disorder and panic have a stronger association between chronic pain and depression. This was also identified by Skevington (1996) and Leeuw et al. (2006).

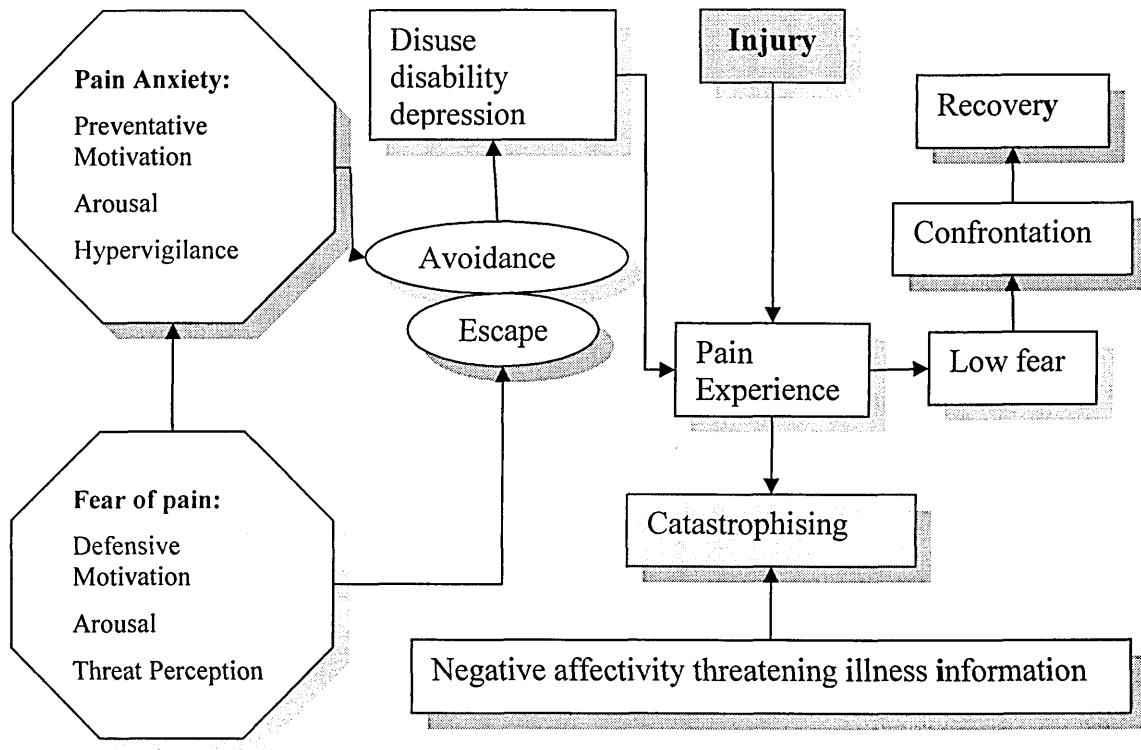


Figure 2.10 - The Fear Avoidance Model of Chronic Pain (Vlaeyen et al, 1995;

Leeuw et al, 2007)

Smith and Zautra (2008) believe that anxiety and depression are responsible for different assaults on the individual in the form of pain sensation. The Smith and Zautra (2008) study looked at the effects of depression and anxiety on weekly pain in women with arthritis. The results showed that anxiety alone was related to elevation in current as well as future pain, in this case the pain experienced the following week.

Additionally anxiety alone was indirectly related to current pain and negative effect. Depression alone was related to current pain through positive affect. They concluded that there is a need for careful study of the differential effects of anxiety and depression and treatments that target these unique mechanisms.

2.8.5 Depression

As I have identified in the anxiety section of this chapter the DSM-IV-TR (American Psychiatry Association, 2000) there is a link between adjustment to long-term conditions such as chronic pain and the individual's mood. Like anxiety, depression can also be present in the adjustment to chronic pain. Depression can also be present alone or with mixed anxiety (American Psychiatry Association, 2000). Morrison and Bennett (2006) explain that there may be a *reciprocal* relationship between depression and pain. People who are depressed may feel unable to cope with their pain and limit their activity to minimise pain sensation. In a review by Blazer (2009) of depression in later life it is reported that older adult outpatients without significant co morbid illnesses as well as dementia who are treated optimally can exhibit a much better outcome with over 80% recovering and remaining well throughout follow up.

This is in contrast to older adults with a lack of instrumental and social support which Blazer (2009) reports have poor self rated health experience and thus longer time in remission. This particular aspect of late life depression has relevance to this current study, in that perceived or anticipated social support in groups may benefit older adults experiencing depressive symptoms. In respect of this Blazer (2009) posits that the association between late life depression and impaired social support has been established for many years. Blazer (2009) also identifies that a better outcome for older adults with depression has been reported when they attend self management and education groups.

Depression has relevance to this current study in that the pain literature suggests a link between chronic pain and depression and there are two main theories. One theory is that pain is the catalyst for depression because it is known to cause so much disruption in people's lives which results in an association with negative emotions, for example when some people experience chronic pain it leads to feelings of hopelessness and helplessness, it can interfere with positive as well as enjoyable activities leading to isolation and frustration. Tang et al., (2008) believe that there is evidence of an association between chronic pain and the clinical diagnosis of depression in a sample of those receiving formal health care for chronic pain as well as in the general population, they also suggest a link between mood status and perception of pain but do agree that it is much harder to establish the extent to which pain causes low mood and *vice versa*. The second theory is that if the person is experiencing negative emotions at the time of the trauma then evidence suggests that they develop pain, which can become chronic in nature. Young Casey et al (2008) believe that the emotional state of the individual at baseline (the point at which the pain sensation becomes apparent) has a bearing on the outcome and development of their chronic pain.

In general depressive disorders are common amongst the general population and are thought to affect at least 1 in 5 (20%) at some point in their lives (Lee et al, 2007) but for people with chronic pain the prevalence rate can be much higher at between 30 to 56% of those with chronic pain according to Lee et al. (2007). As yet there is no definitive link that depression can cause chronic pain. Tan et al. (2008) comment that the argument remains largely unresolved because the data are not conclusive as there are research findings suggesting that people with depression can have a higher tolerance to pain than people without depression. They also add that the more a person reports depression, anxiety, pain severity and pain interference the more disabled the person is likely to become.

2.8.6 Self Efficacy

As we have seen psychological factors play an important part in the way that an individual can perceive chronic pain and the different degrees that it affects them. Bandura (1974, 1977) in his seminal study suggested that perceived self efficacy doesn't just have a directive influence on choice of activity and settings but through expectations of success it can also affect coping efforts. Accordingly, Bandura (1974, 1977) explains that not only can efficacy expectations determine the amount of effort expended by the individual but also their persistence in the face of obstacles and aversive experiences. Therefore the stronger the individuals self efficacy the more active their efforts are. So those who persist in subjectively threatening activities that are in fact relatively safe will gain corrective experiences that reinforce the sense of efficacy, thereby eventually eliminating their defensive behaviour (Bandura, 1974, 1977).

This was demonstrated in an experiment by Bandura et al (1987) where participants were tested for opioid and non opioid mechanisms of pain control through cognitive means and the relation of opioid involvement in perceived self efficacy. Thirty six men and thirty six women participated. They were taught cognitive methods of pain control they were administered a placebo or received no intervention. Their pain tolerance was then measured at periodic intervals after they were administered either saline or an opioid antagonist that block the actions of endogenous opiates. The results showed the effectiveness of cognitive control and to the influential role that perceived self efficacy plays in the process. Cognitive control strategy training it was found, increased perceived self efficacy to endure and alleviate pain. Enhanced perceived self efficacy gave a significant increase to the tolerance of pain. The changes that were achieved by cognitive control in both perceived self efficacy and pain tolerance far surpassed those by the placebo and control conditions. In the placebo group the participants believed they were better able to withstand pain with the aid of alleged analgesics. However the success in reducing experienced pain depended on effective exercise of pain coping skills which medication alone does not provide.

In addition Rokke et al. (2004) believe that not only is self efficacy and perceived control important aspects of pain control but choice also has major implications. Their research showed that providing a choice of coping strategies had the potential to improve tolerance of induced laboratory pain. Rokke et al (2004) suggest further that choice is useful in part because it influences perceived control and allows an individual to select a coping strategy that fits their personal skills and experience. However they do identify that the benefits of choice are limited to those who believe that they have the skills to cope. They found that those with high self efficacy tolerated higher levels of laboratory induced pain when given a choice of coping strategies compared to when they were not given a choice. They also reported that when participants were given a choice of coping those with high self efficacy reported lower levels of pain even when higher levels were induced. Those with low self efficacy, being given a choice did not help either in terms of level of shock tolerated or the reported amount of pain experienced. This has relevance to this current study as support groups could provide self management and choices of coping strategies which may result in an increasingly positive outcome.

With regards to self efficacy and gender Miller and Newton (2006) report that self efficacy differs between male and female. Drawing upon previous discussion on page 39 we are aware that females have a greater tendency to report pain to health professionals. When males self report pain they often have difficulties in explaining the extent of their pain experience (Brooks – Brunn and Kelser 2000). Miller and Newton (2006) theorise that Western societal influences on self efficacy can impede self reporting of pain amongst males.

Males often believe that they are the stronger gender and that it is a *negative standard* to have or report pain (Nayak et al. 2000). However, according to Brooks – Brunn and Kelser (2000) females think that it is appropriate to report their pain to others which may stem from both societal influences as well as self efficacy.

As discussed on page 36 the literature is mixed as to whether or not there is a difference in chronic pain experiences across age groups. Regarding self efficacy Artistico et al (2003) tested the hypotheses that age difference in both self efficacy perceptions and problem solving performance would vary as a function of the ecological relevance of problems to young and older adults. They found that compared to younger participants the older age cohort had lower perceived self efficacy and performance on a traditional cognitive task, in this case the tower of Hanoi problem. In everyday problem solving tasks that were common to both older and younger adults the difference between them was smaller but older adults generated fewer problem solving solutions than their younger counterparts. On ecological problems that were common amongst the younger age group it was proved that younger adults had higher levels of self efficacy and outperformed older adults substantially.

According to Griffiths et al, 2007) Bandura's identification of the importance of self efficacy has influenced self management programmes such as the Expert Patient Programme (DoH, 2001). The key predictor of successful behaviour change is confidence (self efficacy) in the ability to carry out an action and expectation that a particular goal will be achieved, this also known as outcome expectancy (Griffiths et al 2007). This ability to change behaviour has a bearing on this current study where according to Subramaniam et al (1999) the purpose of support groups is that participants learn in a context that is controlled by them and requires little or no professional input. This will be discussed further in chapter three.

2.8.7 Locus of Control

The concept of locus of control was developed originally by Rotter (1966). The full title of the construct is *The Locus of Control of Reinforcement*; this is a salient point because giving it this name Rotter (1966) was bridging behavioural and cognitive psychology. According to Horn and Munafò (1997) the locus of control is related to self efficacy. Rotter (1966) proposes that people have either *internal* or *external* locus of control. Horn and Munafò (1997) also suggest that the locus of control is the results of earlier experiences. For example Rotter (1966) suggests that internality is the result of consistent use of reward and punishment for behaviour in childhood.

Externality rises from inconsistencies, meaning that predictions about the results of one's actions are difficult or impossible. Contingencies such as rewards and punishments mean that individuals hold beliefs about what causes their actions have.

To further illustrate Horn and Munafò (1997) recognise that internal people see success as a reward for hard work, and failure is seen as the results of poor effort and laziness. Accordingly Rotter (1966) proposes that people with an *external* locus of control believe that their own actions are irrelevant to what happens to them but that it is fate that determines success and failure.

Locus of control was taken up with enthusiasm in the field of health psychology (Horn and Munafò 1997). The concept has gone through several changes including the division of external influences into *chance* and *powerful others* (Levenson 1981). As well as the development of a Multidimensional Health Locus of Control (MHLC) developed by Wallston et al (1978), who defined powerful others as health professionals families and friends.

Individuals with chronic pain who have internal locus of control believe that their own efforts are likely to affect the future course of the pain (Crisson and Keefe 1988). Meaning that they are likely to develop and use coping strategies in order to minimize, tolerate and reduce their pain (Copp 1974). In contrast those with external locus of control may have differing set of pain coping strategies (Crisson and Keefe 1988). Crisson and Keefe (1988) theorise that the future course of the external's chronic pain is more likely to be dependent on the interventions of powerful others such as medical professionals, carers or even factors such as chance, luck or fate. Making them rely on more passive pain coping strategies which can result in the view that such strategies are ineffective (Crisson and Keefe 1988). This point is of great importance for this current study as locus of control links with self efficacy.

If locus of control is linked to age then older adults who access and participate in support groups do so because they have a stronger internal locus of control.

Skevington (1983) demonstrated that those with an orientation to chance locus of control towards pain are more depressed than those with internal orientation. Crisson and Keefe (1988) also found that individuals with chance orientation were likely to receive high Helplessness factors of the Coping Strategies Questionnaire (Rosentiel and Keefe 1983); they also reported ineffective coping strategies when it came to controlling and decreasing pain. They were more likely to catastrophise and avoided increasing their activity to cope with pain.

2.8.8 Coping Strategies

A coping strategy questionnaire was developed by Rosenstiel and Keefe (1983) to assess the strategies employed by individuals with chronic lower back pain (Appendix 1, page 406). The questionnaire was further developed by Brown and Nicassio (1987) who proposed that irrespective of their type, coping strategies could be classified as either *active* or *passive*. Their theories are based on the relationship that the coping strategies have to the pain and the psychosocial functioning. Active coping strategies are identified by Mercado et al (2005) as requiring the individual to take responsibility for pain management. Also active coping strategies require that the individual attempts to control the pain or function in spite of it (Brown and Nicassio, 1987; Mercado et al, 2005). In contrast passive coping strategies involve giving the responsibility for pain management to an outside source or even allowing other areas of life to be adversely affected by the pain sensation (Brown and Nicassio, 1987; Mercado et al, 2005).

In conclusion Mercado (2005) like Rosenstiel and Keefe (1983) found that those who employed passive coping strategies were most likely to experience chronic disabling pain. In contrast to those who employed active coping strategies which could include the decision to participate in support groups.

Summary

There are a number of psychological implications for those experiencing chronic pain as this section of the chapter has recognised. In the literature these issues such as catastrophising are reported as responding to input from psychology/psychiatric professionals. A number of the psychological issues may be preventative to motivating the older adult individual into seeking membership of a support group. In the next chapter I will explore the purposes of support groups and how they may be able to provide support for those experiencing chronic pain.

Chapter Summary

This chapter has explored the various models/frameworks used to explain chronic pain.

The current definition of chronic pain has also been discussed. The operational definition of older adults who will be the focus of this current study has also been defined. The exploration of the models/frameworks has helped to illustrate that the nature of chronic pain has an effect on numerous aspects of an individual's life. These include physical, psychological and social functioning and impact on quality of life.

This chapter has also identified that chronic pain is further compounded for some older adults because there is a belief that it is a manifestation of a normal part of the ageing process. The negative attitudes of some health professionals which manifest in anecdotal comments relating to pain and their age are not helpful for older adults to understand that their experience is not a part of the ageing process. There is also evidence that amongst some older adults there is a general disillusionment regarding the formal healthcare system and what it can offer them in the alleviation of their symptoms. These factors may contribute to their decisions to seek alternatives including support groups. This belief concerning chronic pain in many older adults is combined with a reduction of their social networks which may also be viewed as normalisation of the ageing process but it should not be viewed in this way and has the potentials to decrease health status and quality of life.

Although aspects of this chapter would suggest that the consequences of chronic pain would reduce motivation to become a member of a support group. There is evidence that for some older adults living with persistent pain is not necessarily an obstacle to living a satisfactory life. They consider that the consequences pain has on their daily lives can be more problematic than the pain itself (Kumar and Allcock, 2008). This would suggest that the support offered by such groups will need to be broad based and the broadcasting of information should be multi-formatted which would reflect the complexities faced by older adults experiencing chronic pain.

In the current chronic pain literature there are a number of factors that could potentially help to explain why older people may access and utilise a support group. These factors are related to the affects that chronic pain has on their psychological, social and illness behaviour. Psychologically older adults can perceive their self efficacy as being lower than a younger cohort. Individuals' locus of control is linked with self efficacy as well as age which offer further explanations of the psychological influences of decisions to join a support group. Those with stronger internal locus of control may be more willing to access support groups because of their internal orientation. Socially older adults like other age cohorts need to feel valued and respected. Some older adults are more at risk of social and emotional isolation because of a reduction in their social network, reduced contact with their families and a desire not to mix with others in their cohort. These social aspects of chronic illness and agedness may also contribute to their decision to access support groups.

Chapter 3 - Support Groups

The aim of this chapter is to explore the support group literature to identify an operational definition of the groups to be sampled in this current study. The literature of support, self help and other groups that offer support will be reviewed and their distinctions will be reported. In addition self management programmes such as the Expert Patient Programme and Challenging Arthritis have emerged in attempt to help support individuals to manage their chronic illness (DoH, 2001).

The support group literature will also be explored to identify motivating factors for joining a support group and the benefits of participation. Primarily these factors include the need for social support, obtaining information as well as psychosocial factors such as loneliness. There are four components of social support (Langford et al, 1997) including appraisal, emotional, informational and instrumental support. However in the reviewed support group literature social support is reported separately from informational support and appraisal and instrumental support are not highlighted. This chapter will review chronic pain, long term painful conditions and cancer support group literature to identify factors that will influence this current study.

3.1 Operational Definition of Groups to be studied

This section of the chapter will identify an operational definition for the groups to be sampled in this current study. The terms self help, mutual aid and support groups are interchanged in the literature which suggests that there is very little difference between each of these groups. However, there are subtle differences; mutual aid is commonly

used in the literature from United States of America (USA). This is in contrast to literature from the Europe, United Kingdom, Australia and New Zealand.

Prior to the operational definition I had some experience of support groups from both my nursing and pharmaceutical careers. Using this previous experience of support groups, has helped me to identify the criteria of the groups that I would like to sample for this study. These include 1) groups that are peer led 2) groups with no or limited professional input 3) groups that meet regularly but do not require regular attendance 4) groups that do not have a limited length of membership. The support group inclusion and exclusion criteria are further described in Chapter five, page 205.

3.1.1. What is a support group?

In the literature there are identifiable differences between support groups and self help groups. Support groups are said to be led by non-professionals and also have a flexible or open membership (Helgeson and Gottlieb, 2000; Munn-Giddings and McVicar, 2006; Charlton and Barrow, 2002). This is in contrast to self help groups that are reported to be professionally led with fixed or closed membership (Helgeson and Gottlieb, 2000; Munn-Giddings and McVicar, 2006; Charlton and Barrow, 2002). In addition Adamsen and Rasmussen (2001) posit that support groups are identifiable because they possess certain characteristics; they are anti-bureaucratic organisations, spontaneous, reciprocal, and they encourage personal participation without professional input. In contrast Shepherd et al (1999) believe that illness support groups do have some level of professional involvement such as an advisory capacity or as a guest speaker at meetings. The role of professionals in support groups is further explored on page 125.

3.1.2 Purpose of Support Groups

The literature reports that the primary purpose of support groups is to provide an opportunity for people with a common issue to come together, share their experiences and concerns, and learn in a context that is controlled by the participants with very little or no professional input (Subramaniam et al, 1999; Davidson et al, 2000; Gottlieb, 2000). These functions have resulted in support groups being described as another form of treatment (Hatzidimitriadou, 2002), this description is also based in the history of support groups as emergent from grassroots movements originally as an alternative to existing treatment. Historically support groups have their roots in the United States of America (USA) and dates back to 1935 with the emergence of Alcoholics Anonymous (Adamsen and Rasmussen 2001).

Davidson et al (2000) believes the power of the approach of support groups lies in collective wisdom. This collective wisdom is born through the shared experience of participants rather than through professional training or style of the leader. Support groups share commonality with self help groups in that they create peer culture (Gottlieb 2000). This culture is based upon mutual disclosure, aid and a sense of belonging that derives from mutual identification (Helgeson and Gottlieb 2000). These cultural factors influence the outcome measures of group membership. Among the most frequently mentioned outcomes are: increased social support and networks, empathy, a sense of belonging, personal empowerment, information and education, and new coping strategies (Subramaniam et al, 1999; Hatzidimitriadou, 2002)

In addition to the support groups there are a number of self management programmes, these groups are peer led with minimal professional input. However in contrast to support groups there is a requirement to attend all presentations and length of the course consist of 2 hourly sessions over 6 weeks (Barlow et al, 2000). These programmes will be discussed further on page 117.

In conclusion the operational definition of the groups to be sampled is a combination of my previous group experience as well as the descriptions proposed by Adamsen and Rasmussen (2001) and Shepherd et al (1999). The definition of a support group for this current study is a group that is primarily non-professionally led with or without minimal professional input and has open or flexible membership (Shepherd et al, 1999; Adamsen and Rasmussen, 2001). Professional involvement in groups is further described on page 125.

3.2 Support Group Literature

The search strategy was conducted using CINAHL, Ovid and ASSIA. Throughout the literature it was apparent that the term support groups were interchanged with self help and in the United States of America mutual aid. Therefore the key words used for the search included 'self help groups', 'support groups' and 'mutual aid groups'. There were 705 matches; this is in contrast to cancer support groups which using the same search criteria resulted in 1167 matches. A narrowing of the search was performed, excluded was *African Trade Self Help Groups* which appeared in the initial search. Included were qualitative studies, older adults and non-cancer the matches were then reduced to just 12. Quantitative studies that measured outcome and benefits of group participation were also included. Of these 12 only one referred to an illness support group, Parkinson's

disease. In ASSIA there were 3 matches and Ovid 11 matches. Included in these matches were over fifties dance and exercise classes. In contrast to the results of the general support group search the same criteria for cancer support groups maintained the 1167 matches from the previous search.

Aspect	
Population	The groups included in the literature review were chronic pain, chronic conditions which had a symptom of pain, studies that had representation of those aged 55 and older
Motivation to Join	Studies that reported on why members chose to join, their motivation(s) and the recruitment strategy used to encourage them to attend.
Perceived Benefits	Studies that reported the perceived benefits from older adult group members. Groups that promoted self management activities
Study Designs	Epistemological studies were included to quantify the number of groups in the UK. Qualitative studies were included that reported the perceived benefit of participation from the point of view of members. Quantitative studies that measured outcome and group benefits were also included. Although sample sizes were small in some studies which affects representation.

Table 3.1 - the methods used for the search strategy of this study

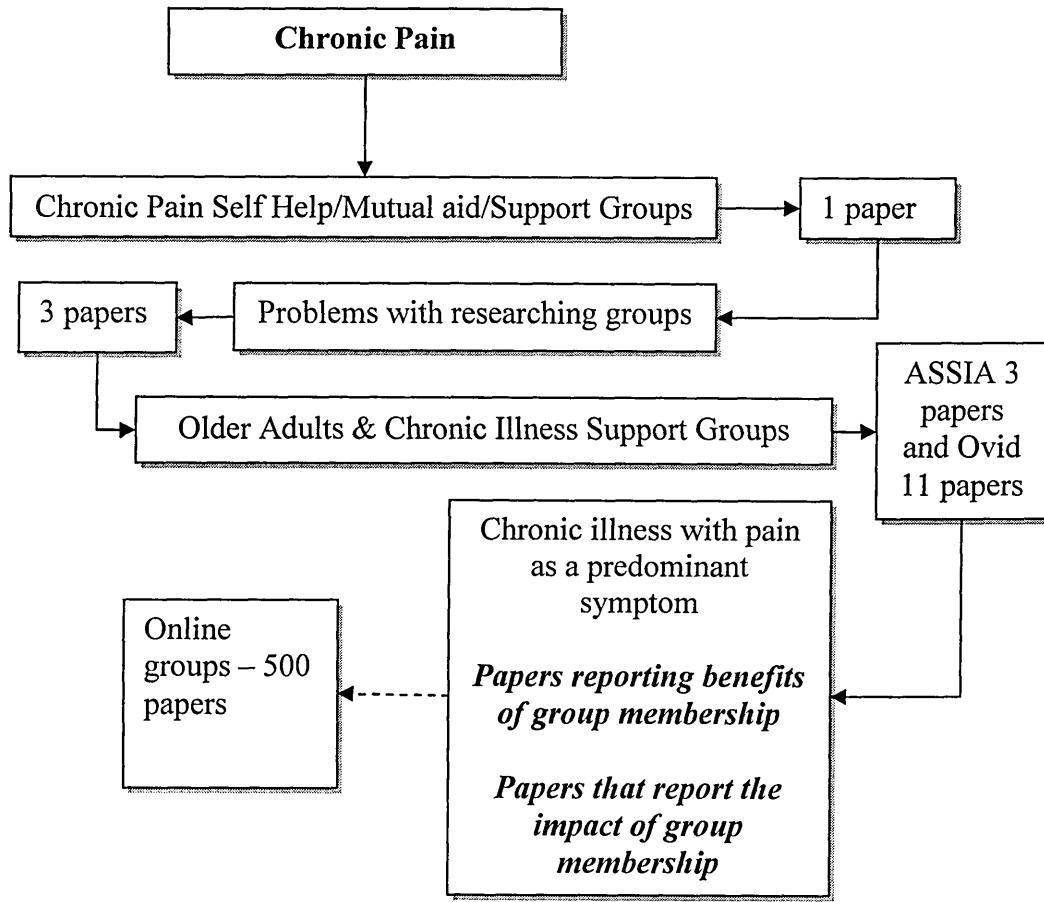


Figure 3.1 - the flow of the support group literature search

Initially a search was conducted for papers from the years 1998-2008 but this widened to 1970-2008 due to lack of results. The search strategy is further presented in figure 3.1. The results of the review of the literature suggest that there is very little attention paid to older adults and support groups. The focus of older adult studies is somewhat limited to dementia, Parkinson's disease or issues for the carer of the older adult (Gottlieb 2000). Borkman (1982) suggests that the lack of studies is more to do with older adults not being interested in joining support groups that focused on the problems of *ageing* and *agedness*. The review of the literature suggests that there is an upsurge of

studies in online support groups. These groups are not the focus of this current study and this will be discussed further on page 159.

Historically, according to Katz (1981) the lack of research and literature regarding support groups generally is not a new phenomenon. Despite the publication of Kropotkin (1901) *Mutual Aid: A Factor in Evolution*; support groups received little attention from academia in the first six decades of the 20th century (Katz 1981). The exception is a study by Bales (1944) focusing on the therapeutic role of Alcoholics Anonymous. Katz (1981) posits that despite the growth of support group organisations in the 1960s there had only been the occasional descriptive case study or general surveys. In the 1960's there was considerable acceleration in support group creation as well as parallel interest from clinicians (Katz 1981). Empirical studies at the time did produce findings pertinent to aspects of their organisation and operation according to Katz (1981).

In the 1970s Katz (1981) describes interest in support groups by sociologists as a striking upsurge in contrast to the previous neglect. This upsurge is attributed to social development itself according to Katz (1981). For numerous reasons self help activities became salient in the social life of the 1960s and 1970s and as a consequence they could no longer be ignored (Katz 1981). This attention brought with it realisation that support groups provide a natural setting for investigating social structures and social relationships (Katz 1981). Despite the upsurge reported by Katz (1981) there remains a literature deficit of the use of support groups by older adults experiencing chronic pain. A possible reason is offered by Butow et al (2007) that optimal outcomes cannot always

be clear because support groups differ marginally in their content, process and structure.

Studies with a focus on *illness* support groups report mainly on cancer as well as cardiac interventions and disease.

The librarian assigned to the Faculty of Health and Wellbeing was contacted and a search for strategies or policies by the government of the United Kingdom (UK) was conducted. The theory being that the UK government may have implemented strategies or policies that had a direct influence on support groups. The search included the online National Archives, the British Library and the Department of Health (DoH) website. The terms self help group, support group and mutual aid were used as key words. The results of the search did not identify any specific intervention. In 1991 the National Health Service (NHS) reformed to be less centralised and to focus on local needs (NHS 2008). This has led to the creation of NHS trusts each responsible for the health of a geographical location. In response local trust documentation was sourced but this identified nothing significant.

According to Munn-Giddings and McVicar (2006) much of the current evidence base regarding the benefits of group membership is from the United States of America (USA). In addition Purk (2004) reports that previous studies have focused on individual group experience as well as practical guidance. Helgeson and Gottlieb (2000) remark that from the literature very little is known about the characteristics of those that are more likely to be attracted and benefit from joining a support group. Helgeson and Gottlieb (2000) also believe that there is a deficit in the data of published literature regarding those who refuse to participate and those who drop out of support groups.

Despite the age of the current limited literature, citations and references are still made to studies that are over 20 years old. Even when support group studies were described by Katz (1981) as increasing, Trojan (1989) reported that the state of research on the benefits of support groups remains unsatisfactory.

3.3 Support Groups in the United Kingdom

Despite the lack of literature and research the popularity of support groups in the United Kingdom (UK) continues to grow (Adamsen and Rasmussen, 2001; Dibb and Yardley, 2006; Munn-Giddings and McVicar, 2006). There is little reliable population data available, however in the year 2000 it was estimated that there were approximately 23400 support groups in the UK (Munn-Giddings and McVicar, 2006). Elsdon et al (2000) found 259 groups in the Nottingham area of the UK translating to 0.4 groups per 1000 of the population. This figure is slightly more than the number of National Health Service (NHS) dentists per the populace of England and Wales which in 2004 was 0.386 per 1000 according to Boulos and Phillipps (2004).

3.4 Issues with the Research of Groups

McDermott (2005) believes that the complex character of all groups makes it difficult for researchers to understand or measure what is going on in a group. This factor challenges research design. The complex characteristics are the multiple layers of intersecting interaction and fluid meaning which occur over time and within a context all contribute into making the experience and the process of a group (McDermott 2005). Everyone in a group becomes both a participant and observer, power shifts as meanings are constructed, negotiated, challenged or allowed to prevail (McDermott 2005). Combinations of all of these factors lead to more questions for the researcher with reference to research design. McDermott (2005) recognises these issues which are

presented in table 3.2. Of interest to this current study are the benefits and limitations of support groups, the severity of the problem which brought the individual to the group, the motivation of the group members and the social support available to them.

Study process or outcome
Comparisons of group or individual interventions
Benefits and limitations
Group leader and group participants' characteristics
Severity of problems which bring people to a group
Motivation of group members
The social support available to them

Table 3.2 – Questions for researchers regarding research design (McDermott, 2005)

The researcher's epistemological position determines the validity and reliability, the trustworthiness and authenticity of evidence from the study of groups (McDermott 2005). The discussions regarding my epistemological stance in this current study are discussed within chapter five, page 200.

Recognising issues of studying group McDermott (2005) believes that there are two different researcher locations when studying groups; insider or outsider. The outsider location is simply defined as a *researcher only*. In contrast to the insider location, this is described as practitioner-researcher. The paper by McDermott (2005) is salient to this current study and will be discussed in more detail in chapter five.

3.5 Chronic Pain Support Groups

The literature search identified only one chronic pain support group paper by Subramaniam et al (1999). In this paper Subramaniam et al (1999) identify that there is vast literature regarding support groups for many health problems and related

difficulties but they also recognise that very little is written about groups for people with chronic non-malignant pain. There are also debates regarding the impact of pain support groups, with positive and negative outcomes being possible (Subramaniam et al, 1999). In this context the negative effect on group participants has been identified as reinforcement and maintenance of pain behaviours, pain related dysfunction and assumption or maintenance of the sick role (Subramaniam et al, 1999). In addition to the negative effect from a behavioural perspective, Subramaniam et al (1999) also reports there may be cognitive issues such as disempowering focus which may engender a sense of helplessness that could lead to adverse psychosocial and functional consequences. This would suggest that in severe cases support groups may be a barrier for some people to manage their chronic pain effectively. Subramaniam et al (1999) remark that previous studies with support groups have relied on retrospective report and evaluation and have not assessed the process of group function. In addition to group function Subramaniam et al (1999) study observed and recorded the development, evolution and impact of a single pain support group. The study also documented group processes and activities which as relevance to this current study in that they helped form an observation schedule which is further discussed in chapter five. The difference between Subramaniam et al (1999) and this current study is that it may not be possible for me to primarily observe the development and evolution of the sampled groups as they may already be established. Further Subramaniam et al (1999) also evaluated the impact of the group as perceived by the members and also their partners/carers. It is the intention of this current study to evaluate the sampled groups through semi-structured interview of the chronic pain accounts of older adult group members.

In the Subramaniam et al (1999) study thirteen participants were sampled, the mean age was 53 years old and the age range of the group was 36-69 years old. The age range for the group is quite broad but limited to the lower end of the operational definition of older adults for this current study. There are possible reasons for this, I have identified in chapter 2 page 38 the most salient is that pain sensation is reported to diminish in people aged 65 years and older. The predominant presenting pain experience in the sample was lower back pain. Females were the most represented gender at 75% of the sample. This helps to confirm my suggestion made in chapter 2 that females could be the dominant gender in support groups.

Subramaniam et al (1999) study consisted of three phases 1) the initial semi-structured interview as well as standardised measures 2) attendance and tape recording five consecutive meetings as well as six committee meetings 3) the follow up semi-structured interviews and completion of standardised measures which were conducted approximately 5 months after the initial interview (Subramaniam et al, 1999). The semi-structured interviews focused on clinical and demographic information, knowledge and previous experience of support groups, expectations of the support group and family and social support. The standardised measures included present pain and health status, pain related health service utilisation in the last 3 months. There was an encouragement to interview the participant with their carer/partner. In these interviews the carers/partners perception of their caring role, changes in the family following the development of the pain problem, knowledge of support groups and their expectations about group participation was the focus. There is no explanation as to why the follow up interview was conducted 5 months following the initial interview. The length of membership of support groups is recognised in the literature as being limitless and

casual, for example Cooper and Burnside (1996) identified that some members of their group only attended two or three meetings whilst other attended for a longer time. On further questioning of group participants Cooper and Burnside (1996) concluded that the number of attendances of a group meeting was not a measure of group satisfaction. They suggest that feedback from group participants' provides a valid measurement of satisfaction. There is also evidence to suggest that a lengthy membership of a support group can have negative impact on participants including negative beliefs about support groups as well as issues with perceived control of illness which may result in less active coping (Grande et al, 2006).

In the initial interview of the Subramaniam et al (1999) study, participants described using a variety of coping techniques which included exercise programs, acupressure, relaxation techniques, pool activities and walking. Others also described using pacing strategies and distraction for pain management. They identified seeking new information on pain management as the major reason for joining the group.

The data gathered in the initial interview regarding the expectation of the pain support group indicated that social opportunities that may be available from the group were primary. The participants thought that they lacked support from their existing support network; this is despite having friends and family living nearby but was particularly apparent regarding their pain problem.

The study data suggested that membership of the chronic pain support group resulted in the participants experiencing clinically significant outcome. Subramaniam et al (1999) identified benefits of group participation and are presented in figure 3.2 on page 110. A

number of these findings are of interest to this current study such as additional education, improved health related behaviours, exposure to new coping resources and an enhanced adaptation to the challenges of chronic pain.

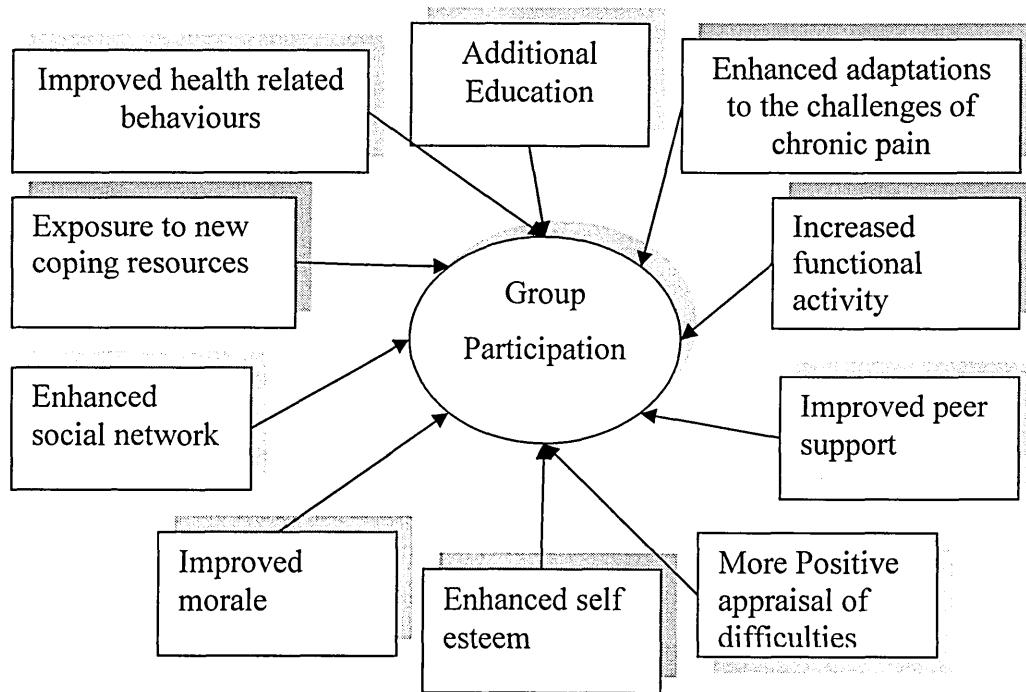


Figure 3.2 : The outcomes of chronic pain support group participation

(Subramaniam et al 1999)

In contrast to the Subramaniam et al (1999) study I will not be using quantitative methods within the current study. Subramaniam et al (1999) identified that the interpretation of the quantitative results of their study should be considered tentative due to the small sample size and the lack of a control group. This may suggest that for this current study the population of the sampled groups may be small due to the casual and flexible approach to group membership (Munn-Giddings and McVicar, 2006) which is viewed as a positive attribute of group membership (Cooper and Burnside,

1996). Elsdon et al (2000) estimated that around 15 members actively attend meetings; they suggest that groups may have a larger membership than those who regularly attend meetings (Elsdon et al, 2000). Additionally a larger group may impact on the intimacy which is identified as possibly helping to inoculate a group from disbanding (Wituk et al, 2002). Elsdon et al (2000) suggests that those who do not actively attend support group meetings do receive newsletters, information as well as minutes from meetings.

Subramaniam et al (1999) reported that the chronic pain support group in their study delivered other formal and informal activities. These included the publication of newsletters. The newsletter reported information about up and coming activities as well as news about members and short articles focusing on pain management. There were also social activities such as day trips organised by the group. Emotional support was provided by the group in the form of telephone support. Outreach was also provided for members that were experiencing difficulties, the nature of which is not reported in the study. These formal and informal activities are of interest to this current study and helped to contribute to the observation schedule which is further discussed in chapter five.

Summary

In the Subramaniam et al (1999) study there is an issue with the participants differing view of the purpose of a support group. This is also reflected in the limited literature and suggests that the support groups have multiple functions. The length of chronic pain experience of the participants in the group is reported as being between 2 and 40 years. This aspect of the group membership is interesting but not really explored further. The aspect of where an individual is *located* in their chronic pain trajectory is of particular

interest to this current study. For example would a support group be helpful to someone who is just coming to terms with their chronic pain?

3.5.1 Groups that offer general support

The purpose of this section of the chapter is to illustrate that if the main purpose of support groups is socially based there are other groups with similar functions. The Subramaniam et al (1999) study suggested that the participants motivation to join the chronic pain support groups was socially based e.g. a chance to expand existing networks, opportunity to share issues with other in similar circumstances. What is not reported in the Subramaniam et al (1999) study is whether motivation to become a group member is multiple. Is there a primary reason as well a number of secondary reasons e.g. socialisation is primary but education support is secondary.

A potential barrier to group membership for older adults was identified in chapter two, Pettigrew and Roberts (2008) reported that older adults do not necessarily want to be grouped with others in their cohort because of verbosity and perceived complaining behaviours. Additionally, Borkman (1982) reported that older adults were less likely to join groups were they felt patronised and are viewed as helpless and dependent.

The importance of socialisation for older adults has also been recognised in a paper by Cheang (2002) who through group observation and interviews found that his study participants were not interested in the structured activities that were offered by the senior centres. This is in contrast to earlier findings by Lieberman (1990) who reported

through observation that older adults were more likely to be attracted to more structured groups. Cheang (2002) study was set in a fast food restaurant where older people congregated in the morning on a daily basis in the United States of America. The participants reported that they wanted to hang out with their friends and what appealed to them about the location and the groups was the informal or casual nature of the gatherings e.g. they could decide when to visit, how long to stay and how much to disclose.

In the literature search two papers emerged reporting similar findings to those of Subramaniam et al (1999) relating to the social aspect of group membership. Paulson (2005) employed a novel combination of qualitative approaches whilst studying subjective experiences of cultural fitness in ageing. The study employed an open ethnographic observation and notes were combined with semi-structured interviews and thematic analysis. The setting for Paulson's (2005) observational study involved two groups; *fitness exercise* for older adults and a *dance exercise* class for older adults. The population of both classes comprised of older adults with diverse abilities and health problems. The 'fitness exercise' group attracted around 25 men and women aged between 50 to 92 years, which is a wider age range than the participants of Subramaniam et al's (1999) study. Some of the attendees came to the class as an element of cardiac rehabilitation or falls prevention. However many came in response to a *crisis* with their ageing bodies such as diabetes, arthritis or difficulties with activities of daily living (e.g. getting out of a chair). The 'dance exercise class' attracted fifteen women aged between 69 and 89 years and one man in his sixties. Members had various illnesses ranging from asthma, arthritis as well as memory difficulties. Like the fitness

group some members participated in various exercise groups. For others it was identified as their main exercise regime.

The benefits of exercise for older adults is reported in the literature, Kemp et al's (2005) reported that 58% of community dwelling older adults aged 65 years and older used exercise as a pain management strategy. Lee and Park (2008) suggest that the association between depression and disability can be moderated by physical activity in older adults. Exercise has been demonstrated to weaken the depression - disability connection in later life (Åberg et al 2005; Lee and Park 2008). Åberg et al (2005) like Dunér and Nordström's (2005) qualitative study identified that; activity, independence and adaptation were important factors for life satisfaction in older adults.

Paulson's (2005) reported that the compliance to exercises by group members continued outside the group, participants tried to incorporate the exercises into their daily lives. Some even spoke of adaptations they had made around the house, like lowering cupboard handles to prevent painful stretches. This suggests an educational element to the group. There was also a social element to the group as some of the members met for coffee after the class. This informal group reflected on how the exercises had changed their lives. Awareness had also been raised about both their bodies and health.

In contrast the dance group's philosophy was to promote 'Togetherness' through encouragement of public performances and social events. Paulson (2005) suggests that

there was a cognitive element to group attendance, although this was not quantified using standard measures, an example was given that concentration was sometimes so hard that they missed jokes made by their instructor. There was also a discipline in the group which meant that members exercised despite back pain, feeling the cold or difficulty in remembering the steps. The group believed that there were definitive benefits to physical exercise. These benefits were expressed mainly in psychosocial terms. Many of the group members attended social events that were organised by the instructor. These social events ranged from coffee mornings, theatre trips as well as public performances at regional rallies. The group also offered therapeutic time-out from difficult lives. Many of the members were widows, some having recently been bereaved. Commitment to the group enabled members to cope with traumas in an active way. Paulson (2005) concludes that participants of both the fitness and dance groups both appear to actively resist ageing.

In this study there were many examples of older adults participating in exercise even when they were struggling. Pain, memory and mobility were all represented as examples of the struggle.

A South African grounded theory study by Nadasen (2007) showed similar findings to Paulson (2005). The grounded theory method was anchored in observation and data. The data was obtained through twelve month participant observation of line dancing classes held in various venues and at various times in Cape Town, South Africa. Open ended interviews were also conducted with women over the age of 60. The results

showed that the emerging themes of the data were perceived benefits. This theme was then divided into three further themes which included; *physical*, *cognitive* and *psychological*.

The majority of the women did not view line dancing as exercise initially nor was exercise the reason for joining. However, women who were experiencing chronic illness were aware that line dancing could help them cope with their illness. Interestingly these women did not consider themselves unhealthy. It emerged through further questioning that the benefits were related to what their bodies and minds were going through at that point in time. Also identified was how they had coped with painful experiences, whether this was emotional or physical is not stated. Nadasen (2007) concludes that there were obvious benefits to the women participating in line dancing. The most surprising of all was that women did not perceive the classes as exercise. The women who were experiencing chronic illnesses such as osteoporosis and diabetes did not intentionally seek line dancing as means of controlling their illness. The participants' perception of the benefits of line dancing is primarily one of enjoyment and expression. There is also a health promotional aspect to activities that are enjoyed which is seen through the resistance of illness and delay to functional capacity. Åberg et al. (2005) reports that older adults identify that activity and independence are significant factors for life satisfaction. The exercise groups were not prescribed by medical professionals or formal self management criteria and demonstrated independent motives of the older adult.

Summary

The inclusion of the findings of these studies is to illustrate the needs of older adults further. The studies by Cheang (2002), Paulson (2005) and Nadasen (2007) suggested that the group participants were motivated towards group membership because of a need to exercise and socialise in an enjoyable way. Their primary reason for joining these groups was not motivated by health problems despite a number of the group members experiencing chronic illnesses. This would suggest that people may not intentionally join these types of groups to seek support for existing chronic illnesses. Those that identified joining as part of cardiac rehabilitation as well as falls prevention do not report whether they referred by health and social professionals. The benefits of membership were reported as exercising but there were also similar to those reported by members of support groups such as social support through traumatic events such as bereavement.

3.5.2 Self Management Programmes

The government of the United Kingdom in their document The Expert Patient (DoH, 2001) define self management programmes as:

"Self management helps people with long-term medical conditions to take responsibility for their own lives. It addresses the 'whole person' and not just the illness and disability. It is about people with chronic disease becoming able to gain greater independence and live healthy, confident lives." (Page 31)

In addition it is also claimed by the Expert Patient Programme (DoH, 2001) that self management programmes could help reduce visits to the General Practitioner and better equip people to manage their conditions with appropriate professional support.

According to Griffiths et al (2007) many health services around the world have adopted this lay led model in the hope that it will deliver cost effective health gains.

Self management programmes such as the Expert Patient Programme originated in the 1980's with the commencement of the Arthritis Self Management Programme (ASMP) (Lorig et al. 1985). The ASMP has been adopted by the voluntary sector and has been given the name Challenging Arthritis in the United Kingdom by Arthritis Care (Hainsworth and Barlow 2003; Shaw and Baker, 2006). Self management is becoming increasingly recognised as developing the confidence and motivation of individuals to use their own skills and knowledge to take effective control over life with chronic illness (DoH, 2001).

Kerns et al (2006) identify that the ability of individuals to self manage chronic pain depends much more on what they do rather than on what is done to them. In addition Griffiths et al (2007) identified the importance of self efficacy in the causal pathways of behaviour change in self management. Increasing self efficacy is a prerequisite for behaviour change which through improved self management may influence health and healthcare use (Wright, 2004; Griffiths et al, 2007). Older adult participants in the Sofaer-Bennett et al (2007) study demonstrated that management strategies for chronic pain were self motivated. The individuals' motivation is implicit in the self management approach in order that they *engage in* and *maintain* treatment recommendations (Kerns and Habib 2004). In some more formal self management programmes, such as the Expert Patient Programme, Koch et al (2004) argue that the 'self' is missing from this type of intervention, they further describe these programmes as being *off the shelf* and *prescriptive*.

Success of chronic pain self management is not only dependant on self efficacy but also other psychological factors such as a need for personal control (Koch et al 2004; Davidson et al 2005). Importantly the choice of the individual is paramount to successful adaptation. Schofield et al (2005) recognised that the ideal situation for many older adults is for their chronic pain to be self managed. Lorig and Holman (1989) believe that if self management interventions are to be judged as being worthwhile they must prove themselves effective over time.

A UK randomised control trial by Barlow et al (2000) was conducted to determine whether the Challenging Arthritis (CA) programme improved perceptions of control, health behaviours, health status. As well as assessment of a change in the use of health care resources. The Challenging Arthritis (CA) course is usually delivered in community settings like church halls (Hainsworth and Barlow 2003). In total 544 participants based in the community were allocated to either an Intervention Group (311), which attended CA immediately or a Control Group (233), assigned to a 4 month wait to attend a CA. Additionally the Intervention Group completed a 12 month follow up. The mean age of the intervention group was 57.3 years and for the control 59.1 years. Mean disease duration was 10.7 years for the intervention and 11.3 years for the control.

The Challenging Arthritis (CA) course comprises six weekly sessions, each lasting 2 hours (Barlow et al. 2000). The sessions are delivered by lay leaders most of whom have arthritis themselves. Leaders are trained by Arthritis Care and course delivery is guided by a manual to ensure consistency of content. The CA is multi-component and

topics include; arthritis information, overview of the principles of self management, exercise, cognitive symptom management (distraction, visualisation and guided imagery), dealing with depression, nutrition, communication with family and health professionals and contracting (Barlow et al 2000).

Contracting involves setting realistic goals that are to be achieved during the forthcoming week (Barlow et al 2000). Participants report back to the group on their achievements at the next weekly session. Participants are also given a copy of *The Arthritis Handbook* (Lorig and Fries 1995), which is used as an accompanying guide to the course. The format of the CA is largely interactive, with short lectures that introduce the topics. There are group discussions, problem solving, role playing and mastery experience which are described as trying out new skills introduced by the CA. The aim of the CA is to enhance perceived ability to control various aspects of arthritis through four major efficacy enhancing strategies; *skills mastery, modelling, persuasive communication and reinterpretation of symptoms.*

Skills Mastery is described by Barlow et al (2000) as the most potent efficacy enhancing strategy. Skills mastery involves learning and practicing appropriate behaviours. The new behaviours are broken down into smaller more manageable ones ensuring that each is successfully executed. Modelling is described by Barlow et al (2000) as technique whereby a realistic positive role model who is successfully managing aspect of their lives serves as a source of inspiration to the participants of the course. Barlow et al (2000) adds that in the context of CA this role model is represented by the course leader. In addition the course participants act as models for their peers.

Persuasive communication is most effective when it involves encouraging participants to attempt a little more than they are currently doing (Barlow et al 2000). The reinterpretation of physiological symptoms is the final type of efficacy enhancing strategy. Participants are taught to distinguish between physiological disease related symptoms like pain, fatigue and arthritis related muscle soreness and similar symptoms that can arise from therapeutic exercise. In addition cognitive symptom management techniques can be used to help overcome feelings of helplessness in response to pain (Barlow et al 2000).

The main outcome measures of Barlow et al. (2000) study were arthritis self efficacy, health behaviours (which included exercise, cognitive symptom management, diet and relaxation), and health status (which included pain, fatigue, anxiety, depression and positive effect). Barlow et al (2000) report that at 4 months the results for the Intervention Group demonstrated that the CA was effective in terms of improving perceptions of control (e.g. arthritis self efficacy), use of self management techniques (e.g. cognitive symptom management, communication with physicians, and exercise), and health status (e.g. fatigue, anxious, depressed and positive mood).

A similar pattern of results were reported at the 12 month follow up for the intervention group. Barlow et al. (2000) reports that the resulting changes in health behaviour and health status were at least maintained in the long term. They also found that pain at the 12 month follow up showed significant improvement but there is an absence of a control group at this assessment time. This means that this change cannot be attributed to the intervention. The CA seemed to have little impact on the use of healthcare

resources at 4 months. Although by 12 months the Intervention Group were making fewer visits to their General Practitioner. All participants in the study showed that physical function was stable throughout its course. However those with osteoarthritis, which is a degenerative condition, in the Intervention Group showed a small decline which was noted at the 12 month assessment. Barlow et al. (2000) reported that even though it is recognised that behaviour change is difficult, the increased use of exercise amongst the Intervention Group was reported as encouraging. This result was even more positive when it was recognised that the Intervention Group maintained the exercises at the 12 month assessment.

This exercise maintenance was despite any additional support. Previously it has been reported that there is a low level of adherence to exercise recommendations among people with chronic disease although this is disputed in the studies by Paulson (2005) and Nadasen (2007). Barlow et al. (2000) conclude that the community based intervention appeared to offer numerous benefits for those with arthritis in the UK and could be a useful adjunct to medical care.

Summary

The Barlow et al (2000) study reported on the content and the anticipated outcomes of the challenging arthritis course. The support group literature suggests that the content of support groups has a similar agenda to that of the more formal course. The most apparent difference is the style of meeting, which in the self management programmes appears to be curricular based, as well as length of membership which in self management programmes is limited to the length of the course. In addition the length of illness experience may have impacted on the reported outcome results at 12 months. Do

participants who have experienced chronic pain become more *accepting* that a cure may not be found? The results of this would suggest that these individuals may have reduced confidence in the formal healthcare system. As a consequence of this alternative approaches maybe explored. This aspect of the Barlow et al (2000) study is of interest in locating when in the chronic pain trajectory would support group membership have more of an impact.

3.6 Support Group Recruitment Strategy

The open and casual approach to both membership and meeting attendance could impact on continuation of the group. Constant recruitment of new members according to Wituk et al (2002) is an important component in the survival of the support group. A potentially positive aspect of continual recruitment is also identified by Wituk et al (2002) as providing those already attending the group a chance to offer the same type of support they previously received. Without this opportunity existing group members may feel that the group is no longer valued and therefore not needed. Wituk et al (2002) believe that health professionals can play an important role in support group survival. This can manifest itself in many ways such as referring new members to the group and providing advertising space in waiting areas. The group also has a commitment to update medical professionals about changes to venue, meeting times and days.

How a potential group member locates a support group varies according to the literature which reports mixed approaches being employed. The literature has helped to identify potential search criteria for this current study. Dibb and Yardley (2006) proffer that there are two website data bases that provide information of over 2000 illness support groups in the UK but suggest that there are potentially more illness support groups that

do not *advertise* on the internet. This is in contrast to Munn-Giddings and McVicar (2006) who report that databases of UK based support groups are not available. They located the groups for their study by approaching the local Council for Voluntary Services as well as local social services departments.

Butow et al (2007) located groups for their study through a method called snowballing which involves asking group leaders and group members if they were aware of any other support groups. Subramaniam et al (1999) reported that the chronic pain support group in their study advertised widely. These advertisements were through newspaper articles, radio interviews and pamphlets that were made available in various health related locations although there is no report on which media was successful in recruiting members. Wituk et al (2000) studied 253 support groups. The results showed that the majority of new members were recruited by word of mouth. This was followed by newspaper and magazine advertising or asking health professionals. The distribution of flyers and brochures by the group was also reported by Wituk et al (2000) as a successful tool in recruitment. Much of the literature reports that making medical professionals aware of the group has been shown to be successful (Cooper and Burnside 1996; Shepherd et al 1999; Wituk et al 2000; Hildingh and Fridlund 2001; Carlsen 2003). This is despite some support groups initially being established in opposition to professional healthcare in an effort to avoid the passive patient role (Carlsen 2003). Using this method of *referral* allows the individual to make an informed choice. The support of medical professionals can be viewed as a positive aspect of self management.

3.7 Professional Involvement

In the debate that surrounds the definitions of both self help and support groups the input from healthcare and other professionals was a salient issue. The only exception is the exclusion of professional involvement reported in Alcoholics Anonymous, Narcotics Anonymous and Gamblers Anonymous meetings (Shepherd et al 1999; Schiff and Bargal 2000). There are two contrasting debates regarding the level of professional involvement Adamsen and Rasmussen (2001) propose that support groups are free of professional input and Shepherd et al (1999) reporting that in support groups there is some level of professional input and that groups that had shared professional and peer input had increased longevity. The level of professional involvement identified by Shepherd et al (1999) is presented in table 3.3.

Type of professional Involvement
Group Leader
Speaker
Organiser
Source of referral
Consultant
Group Sponsor
Researcher
Advisory Member

Table 3.3: Type of professional involvement in support groups (Shepherd et al, 1999)

Table 3.3 illustrates the extent of professional input and how this can vary in lay led support groups; these can include occasional speaker or an occasional facilitator at group meetings. According to Shepherd et al (1999) group members can be positive about professionals playing the role of advisor to the group but were critical of professionals who tried to dominate the group.

Referral source, speaker, consultant and advisor were the roles most frequently endorsed for professionals by group members (Shepherd et al, 1999). In contrast professionals saw their role as educator and to empower, as well as a referral source and facilitator (Shepherd et al, 1999). These contrasting views can impact on starting a support group as studies by Carlsen (2003) and Marzen-Groller and Bartman (2005) help to demonstrate.

In the study by two nurses, Marzen-Groller and Bartman (2005) established a support group for individuals who had undergone surgical amputation. The group was formed in response to the deficit of information that was available. As both were healthcare professionals they describe a perceived advantage over other non-medical individuals who are setting up a support group. Their knowledge and understanding of the *workings* of local hospitals and other medical establishments was also identified as an advantage through the use of personal and professional contacts. Marzen-Groller and Bartman (2005) also had access to academic literature enabling them to create a model for the support group. Their approach was from a positive view they held about support groups; they report that the groups can help empower individuals through the provision of information and support. However Marzen-Groller and Bartman (2005) planned the meeting from a nurse's perspective despite reporting that nurses needed to be aware that their agenda differs from that of the patient. Their focus for the meetings was based on educational and emotional support. The group members rejected this format in favour of socialisation with other members.

Marzen-Groller and Bartman (2005) acknowledge that the problems they had in getting things right was not due to their professional input as suggested by Shepherd et al (1999) but the availability of academic literature regarding starting a support group.

Despite these issues the group was reported to be doing well, which was reflected in the observation of the continual increase in membership.

Another example of the issue of professional input is reported in a study by Carlsen (2003). Here a medical professor was approached to help start a support group intervention for individuals with Chronic Fatigue Syndrome (CFS). The professor appointed two social workers to plan and lead the group. The group was not a success. Carlsen (2003) believes that this is because of the support group participants had a very different set of criteria from that of the professional initiators. The professionals wanted to give those with CFS the opportunity to share social support. The participants are reported to have had an ambitious long term external objective in mind from the onset. Arguably the objective for the group members was born out of frustration at the lack of medical support for CFS. Therefore they believed that participating in the support group would allow them to develop contact with medical professionals. There was also political motivation as many of the participants believed that the group could take on and challenge the Norwegian National Insurance Scheme. The scheme does not acknowledge CFS as requiring intervention from the welfare system.

Carlsen (2003) also reports that when the medical professor and social workers were setting up the group they were unaware of the participants' aims. This was despite the two groups collaborating from the beginning. This resulted in the two parties pulling in

opposite directions because of the agenda differences. This further resulted in neither party assessing the intervention as successful. Carlsen (2003) believes that the group members chose to keep the agenda hidden because funding for the group was coming directly from the hospital. She suggests that group members believed that this funding would be stopped if their true agenda was unearthed. Despite this Carlsen (2003) suggested that some form of professional input is the correct approach. This is because many group members can have different objectives and reaching a consensus opinion can be time consuming. Subramaniam et al (1999) offers a similar conclusion but in contrast the objectives of the group were achieved through consensus of the group's committee. This committee was appointed in the early stages of the group's development and consisted of group members.

Penney (1997) describes professional involvement to the extent reported in the studies by Carlsen (2003) and Marzen-Groller and Bartman (2005) as being bogus versions of support groups. She adds that support groups controlled by professionals do not empower people and leave them dissatisfied and cynical, although it is agreed that there is a need for some form of professional input as a factor for support group survival such as referrals (Shepherd et al, 1999; Wituk et al 2002).

In social work a model for setting up a self directed group was developed by Mullender and Ward (1991). Although this model is over eighteen years old it has relevance today. Additionally the model (Figure 3.3) was developed for setting up social work groups but is easily transferrable to chronic illness support groups.

Stage A - The Healthcare Professionals Take Stock - this is the preplanning stage and is undertaken prior to making contact with the users of the group. Integrated into this stage are three steps:

Step 1 - Assembling a compatible co-worker team

Step 2 - Establishing appropriate consultancy support

Step 3 - Agreeing on the empowering principles of the work

Stage B - The Group Takes Off - The established team of healthcare professionals engages with the potential group users as partners. The idea here is to build a group along *open planning lines*. This initiates a style of work where the users will set the norms for the group, define and analyse the problems and set the goals.

Step 4 - Open Planning

Stage C - The Group Prepares to take Action - The group is helped to explore the questions What? Why? and How?

Step 5 - The healthcare professionals facilitate the group setting its own agenda issues:

Asking the question - What are the problems to be tackled?

Step 6 - The healthcare professionals help the group to analyse the wider causes of the problem:

Asking the question - Why do the problems exist?

Step 7 - The healthcare professionals enable the group to decide what action needs to be taken, set priorities and allocate tasks:

Asking the question - How can we produce change?

Stage D - The Group Takes Action - The group participants move from recognition to action:

Step 8 - The group participants carry out the agreed actions

At this stage steps 5 to 8 may recur, perhaps several times, before the group moves on. As they raise the participants' confidence they become self reinforcing.

Stage E - The Group Takes Over

The group goes onto see the connections between the what, why and how. To clarify further the group participants extend their attention to the broader issues and wider-scale campaigning. Meanwhile the healthcare professionals move increasingly into the background and may leave the group altogether. As well as *taking over* the running of their group, participants are by this stage, learning to take control of their own lives and of the way other perceive them. Their much improved self-esteem tells them that they have a right to do this.

Step 9 - the group reviews what is achieved

Step 10 - The group identifies new issues to be tackled - reformulating what?

Step 11 - The group perceives the links between the different issues tackled - reformulating why?

Step 12 - The group decides what action to take next - Reformulating how?

Steps 9 - 12 become a continuing process throughout the group's life (Mullender and Ward 1991)

Figure 3.3 – The Self-Directed Group Work Model (Mullender and Ward 1991)

adapted for chronic illness support groups

Subramaniam et al (1999) established their group in a similar way to the self directed group model (Mullender and Ward 1991). At the initial planning stages a small committee of lay members took responsibility for the organisation and operation of the group. With the exception of the occasional input from a clinical psychologist the group generally operated with little professional input. This advice provided by the clinical psychologists helped the group leaders guide the group towards a more positive focus on life with pain. Subramaniam et al (1999) also recognised that group members like those in Carlsen (2003) study had different agendas. Some of the members believed that the group should focus on giving people the opportunity to talk about their pain. This was not supported by the majority of the group. Initially the meetings were held in the morning but due to time constraints of some members there was also an additional afternoon meeting. The meetings followed an agenda from the start but later meetings were less formal. The support groups also included speakers. These speakers were not limited to health professionals but also included people with expertise in disability. Speakers who covered topics that were not related to pain were also invited. These topics varied from home security, updates on driving rules and techniques as well as puppetry. It was felt that the inclusion of various topics may assist members to develop new skills, interests or sources of life satisfaction. Members were also given information relating to available exercise opportunities.

Summary

The groups studied by Subramaniam et al (1999) and Carlsen (2003) suggest that a democratic approach to group purpose is an essential component of development. In the Subramaniam et al (1999) study there is also a suggestion that as the group evolves there is more organic approach to their development which is dependent on a consensus

of members. This can be because of continued group recruitment and the differing needs of individuals. There is also a risk that individual agendas may not be addressed which may result in a general disillusionment of how the groups could help.

3.8 Ethical considerations

An aspect of Marzen-Groller and Bartman (2005) study highlighted the need for ethical considerations when establishing a support group. When they *selected an audience* they enlisted the help of medical consultants who provided the group with a list of patients who had undergone an amputation. Without apparent exception a letter was then drafted and posted to explain the purpose of the group. However nowhere in this study do Marzen-Groller and Bartman (2005) explain the ethical considerations to what they were doing. There are a number of concerns to recruiting in this way. As Marzen-Groller and Bartman (2005) themselves report survival rates for amputees is less than 5 years due to vascular complications. However there was no contingency discussed if they should inadvertently cause distress to surviving family by writing to someone who had died. A much more ethical approach to group recruitment is needed.

3.9 Determining Factors for Participation in Support Groups

Group membership is an intrinsic aspect of human life (Stewart 2005). The quality of the groups can make a contribution to the well-being of an individual. Groups can also be instrumental to other capabilities and can have an influence on people's choices and values (Stewart 2005). The literature suggests that there are a number of factors/determinates that influence an individual in the decision making process regarding support group membership, these are presented in figure 3.4. In addition to the factors identified, Voerman et al (2007) suggests that medical and illness specific factor also has an influence upon the decision to join a support group. This is disputed

by Grande et al (2006) who found that clinical characteristics of the illness was not an important determinate to join which may help to understand the motivation of the members of the groups reported earlier (Cheang, 2002; Paulson, 2005; Nadasen, 2007)

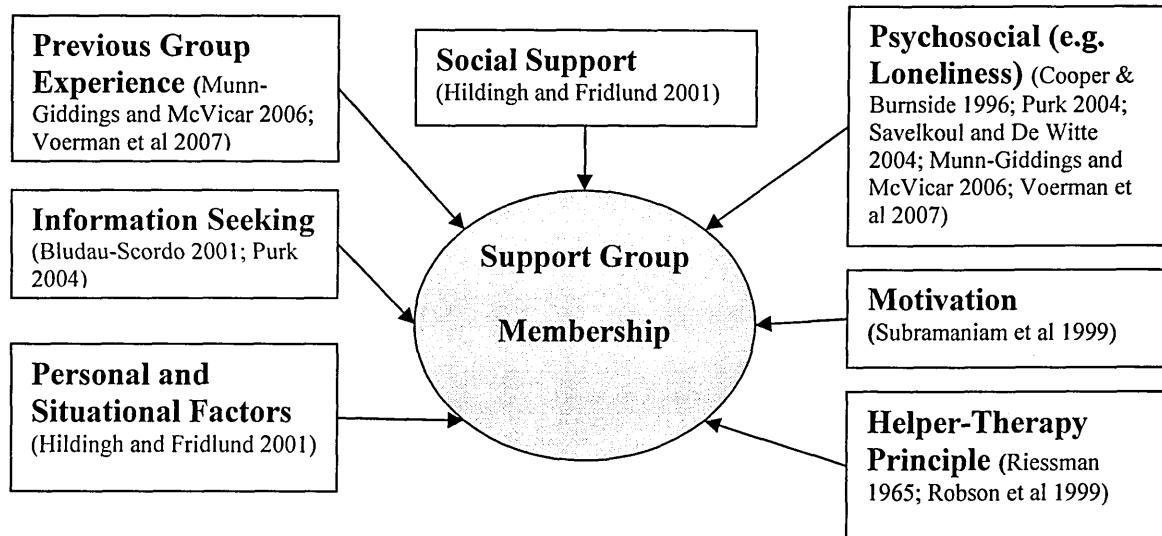


Figure 3.4 - Determining factors in joining a support group

Each of the sections identified in the review of the literature is discussed in the following sections.

3.9.1 Social Support

According to Faulkner and Davies (2005) there is little consensus regarding a theoretical and operational definition for social support. In a review of the literature Langford et al (1997) concluded that social support relates to one or any combination of four broad components (Figure 3.5).

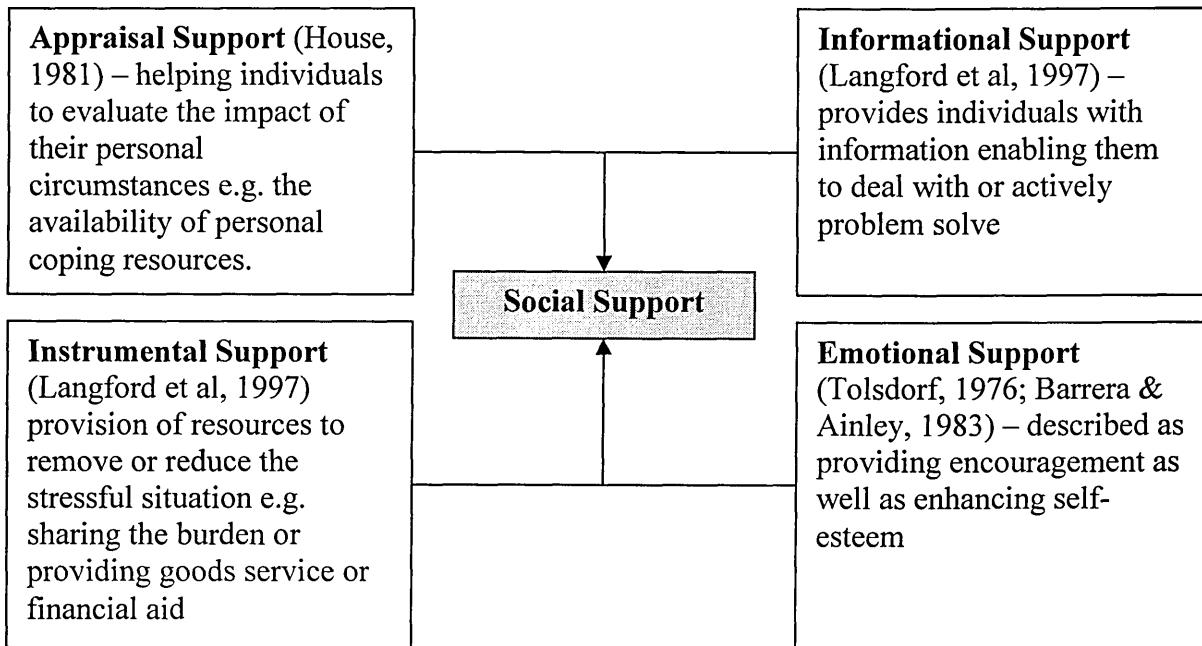


Figure 3.5 - the four broad components of social support (Langford et al, 1997)

As reported earlier in this chapter the support group literature informational and social support outcomes are often reported as separate factors (Bludau-Scordo, 2001; Purk, 2004). In the Subramaniam et al (1999) study information support is also referred to as educational support which is a reflection of support groups being an environment where people learn (Subramanian et al, 1999; Davidson et al, 2000; Gottlieb, 2000) in this social setting from each other.

Acute and chronic stressful experiences such as illness often impose demands that we are unable to address (Hildingh and Fridlund, 2001; Cohen and Pressman, 2004). These experiences are said to put individuals at risk of psychological and physical disease and disorder (Cohen and Pressman, 2004). The provision or exchange of emotional, informational or instrumental resources in response to others' needs, such as in a support group (Cohen and Pressman, 2004) is thought to facilitate coping with these demands and as consequence be protective, this proposal is called stress- buffering

hypothesis (Cohen and Pressman, 2004). It is also reported that in some chronic illnesses social support can affect survival and recovery e.g. social support is known to positively influence survival and recovery in cardiac illness (Hildingh and Fridlund 2001).

In chronic pain the potential therapeutic role of social support is of interest to researchers (Holtzman et al, 2004). The majority of studies regarding social support and chronic pain have focused on its relationship with depression and other forms of psychological distress (Cohen and Pressman, 2004); the findings of these studies have generally indicated that individuals with higher social support experience less depression and negative mood (Holtzman et al, 2004). There are very few studies have investigated social support and health outcomes (Cohen and Pressman, 2004) such as pain severity (Holtzman et al, 2004). However a study by Brown et al (2003) suggests that experimental pain is reduced when individuals provide passive or active support. Passive support was defined in the experiment by Brown et al (2003) as involving the presence of a supportive other, either a stranger or a friend, who is prohibited from communicating support through gestures and comments. In contrast active support in the experiment was intended to mimic naturally occurring supportive transactions and involved the presence of a supportive stranger or friend who makes explicitly supportive gestures and comments (Brown et al, 2003). Overall, according to Cohen and Pressman (2004) the work on stress-buffering indicates the importance of perceived availability of support; in contrast actually receiving support has often been correlated with negative outcomes. Cohen and Pressman (2004) posit that actual receipt of support indicates the need for support as well as its availability. Barerra and Ainley (1983)

report that the most effective support is not asked for but instead is provided in the course of everyday social interactions.

An example of this complexity of social support is reported by the participants of the Subramaniam et al (1999) study. Cohen and Pressman (2004) suggest that we do not generally think of support provided by close family and friends as help and often we are unaware of receiving it. Actually asking for help can impact on the maintenance and quality of a relationship as well as its equity (Cohen and Pressman, 2004) our close relations should know we need their support and respond without a formal request. The participant in Subramaniam et al's (1999) study describe chronic pain as having a multiple impact on their natural social network.

The majority of the participants identified that chronic pain not only had an effect on their own emotions but impacted on family relationships. They identified that there was a particular increase in dependency on family and friends and this was described as being troublesome. This issue manifested itself when participants considered themselves to be a burden. They also thought that the chronic pain had an equal or even a greater impact on family and friends than on themselves. Participants also suggest that tension and conflict had increased between partners. A possible reason for this is a reduced equity within the relationship which was identified by Cohen and Pressman (2004). These factors accumulated and further engendered feelings of isolation, loneliness and a lack of support (Subramaniam et al, 1999). Most of the participants reported that they were involved in few social or community activities. This lack of social contact, generally attributed to their pain problem, had the effect of increasing

their feelings of social isolation. There were also reports of a significant loss of independence which encroached on all aspects of their lives including in some cases financial dependency. They described financial dependency as not only pertaining to the welfare state but also on others within their social network. The result of this was financial stress, which was reported by the majority of the participants. Partners also indicated that the development of chronic pain had led to substantial changes to family routine, roles and activities. Subramaniam et al (1999) found in their study that the participants' expectations and the expectations of their partners concerning the group were consistent. Although it was reported that only two partners attended the meetings. The reason for this was that at initial interview few of the participants wanted their partners to attend the meetings. However, this changed at the follow up interview. Here participants reported that family members should attended the meetings. The participants believed that the perceived outcome would be a better understanding of the situation of the person in pain.

Hildingh and Fridlund (2001) suggest that there are differences in the social support networks amongst rural and urban communities. Two studies from the United Kingdom also suggest that there are differences in the interpretation of social support in rural communities. In the first, Blackstock et al (2006) looked at the social support experiences of people with dementia and their carer's. The study was set in the rural communities of Scotland. Primarily they found that both carers and those experiencing dementia defended their situation through the use of a narrative of idealised rurality. This was evident through expressions of a physical relationship with place as well as a sense of self sufficiency. Older respondents also reported self sufficiency as a key theme

in Heenan and Birrell (2006) study. The study was based in the farming communities of the six counties of the North of Ireland. The older farmers suggested in their interview responses that there was a prevailing culture of social support within the community. Heenan and Birrell (2006) also reported that there were strong cultural factors that restrained their use of certain services. The factors included stigmatisation and pride that was attached to self reliance and were repeatedly mentioned by the individual respondents. The results also showed that obtaining support was multifactorial. There was found to be a lack of reliable information from the health service for individuals. This was also compounded by the stoic culture that prevailed in these communities. Strength of character in the community was judged on the ability to *soldier on* and *suffer in silence*.

This stoicism was apparently noticeable in matters concerning mental and psychological well being. It was also more noticeable in older males than older females. Heenan and Birrell (2006) believe that the problems of rural communities are exacerbated by the approach of the government. This is reported as an absence in appropriate services which has also impeded wider social support. This 'one size' fits all approach by government is potentially very harmful according to Heenan and Birrell (2006). They believe that the present general lack of understanding of the distinct needs of those in rural communities' has negative effects. Heenan and Birrell (2006) also reported that older adults in these communities are seeing an exacerbation of their marginalisation and isolation.

3.9.2 Informational Support

Informational/educational support involves providing individuals with resources enabling them to deal with their issues in an active way (Langford et al, 1997). Tolsdorf (1976) also suggests that it may involve informing individuals where and how they can obtain further advice.

In the social support section of this chapter informational support was identified as a component of social support (Langford et al, 1997). In the support group literature informational support is often reported as educational support (Bludau-Scordo, 2001, Purk, 2004) without a clear definition and reported separately to social support.

In Subramaniam et al (1999) study the primary expectation of support group participation was gathering new information about chronic pain with a focus on management of their particular circumstances. Robson et al (1999) reported that those in support groups are facing or have faced similar issues. This was the case in the Subramaniam et al (1999) study, here participants wanted the opportunity to learn from and associate with others experiencing similar problems. In the outcome of the study Subramaniam et al (1999) reported that although the information provided by health professionals and other speakers was helpful, information from discussions with other group members was seen as particularly important. This led the participants to comment that the support group filled a gap in services, providing support in a way that professionals did not (Subramaniam et al, 1999).

Hildingh and Fridlund (2001) study of a cardiac support group found that participants scored higher than those who didn't pursue informational support. Information support seeking is dependent on a number of factors. These factors are largely subjective and can include what is widely known about the chronic illness as well as the quality and quantity of information given by health professionals to the individual experiencing the illness (Cooper and Burnside 1996; Bludau-Scordo 2001).

The groups that were observed by Bludau-Scordo (2001) are an example of this. In this study the groups were set up to provide information and social support for individuals experiencing mitral valve prolapse. The formation of these groups was in recognition that those experiencing the illness are given very little health information by medical staff (Bludau-Scordo 2001).

The lack of informational support was also highlighted in the study by Cooper and Burnside (1996). Cooper and Burnside's (1996) adult burn support group was formed because a number of issues that were not being addressed by the hospital were identified. These issues related to a need for increased information and longer term support (Cooper and Burnside 1996). The recruitment to the support group through the hospitals burns outpatient department gave Cooper and Burnside (1996) the ability to record the reasons why some people chose not to attend the group. Some of those who chose not to participate considered that they had obtained sufficient information from their individual outpatient sessions. Other reasons were the costs and the long distances involved in travelling to a regional unit where the group was held.

Grande et al (2006) also found that for some, the decision not to participate was because they already had sufficient information already or were not experiencing psychological distress over their illness. Grande et al (2006) argue that those who perceive they have adequate informational support and low psychological distress can still have a role to play within a support group. They can act as role models to other members, helping can have a positive effect on wellbeing. This aspect of the group is comparable to the modelling strategy of Challenging Arthritis as well as the Expert Patient Programme reported by Barlow et al (2000) on page 117.

Participants of the Subramaniam et al (1999) study also expressed that the ability to help each other was a significant expectation of group participation. Subramaniam et al (1999) also report that a minority of the members did not believe that the group had directly helped them. This was because they felt that they were already coping well. They did gain satisfaction from helping others in the group. Grande et al (2006) adds that other reasons for non participation was due to the individuals' negative perceptions of groups. These perceptions included depression associated with membership combined with the burden of listening to the 'problems' of others in the group. Grande et al (2006) commented that when these perceptions were presented to group organisers and existing members they were deemed incorrect.

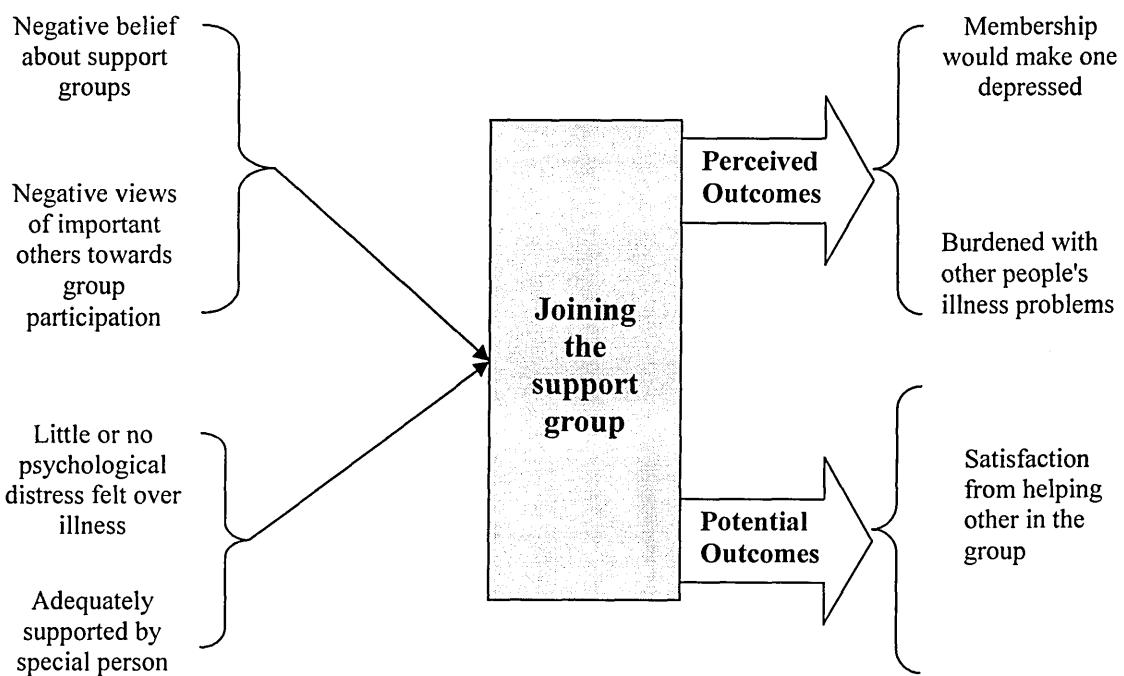


Figure 3.6 Reasons for not joining and perceived outcomes of those with negative views of support groups (Cooper and Burnside 1996; Grande et al 2006).

The conclusion of the Subramaniam et al's (1999) study identified that a major benefit of membership which was reported by individuals was “*gaining knowledge*”. This information gain was split by the participants into two sources; health professionals including other speakers and group members in a discussion forum. Members described information given by health professionals and other speakers as helpful. However information following discussions with other group members was seen as particularly important. Some members also reported that the group was “*the most positive thing that had happened to them in long time.*” A majority felt that the group had an impact in helping them in their daily lives.

3.9.3 Information Standard

The literature recommends that a group should provide informational support to its members (Hatzidimitriadou, 2002). However the standard of the information that is available at support groups may cause harm. In order that there is some form of quality assurance of the available information the Department of Health (DoH) in the United Kingdom (UK) launched the Information Standard (DoH, 2009). Participation of organisations in the Information Standard is currently voluntary (DoH, 2009). The scheme is designed to run independently and will include the input from a range of organisations such as charities, private companies as well as public sector bodies and any other organisation that provides information on health and social issues. Arthritis Care and the Multiple Sclerosis Society were members of the testing network (DoH, 2009) which was set up in the development phase of the standard (DoH, 2009). The inclusion of these varied organisations is to prevent conflict of interest as may possibly be the case if the scheme was to be managed from within the National Health Service (NHS) (DoH, 2009). Therefore the Information Standard certification can be applied in an impartial way (DoH, 2009). Health and social information that has been approved by the organisation will display an Information Standard Quality Mark (Figure 3.7)



Figure 3.7 The Information Standard Quality Mark (DoH, 2009)

According to the Department of Health (2009) the mark has been extensively tested with members of the public, health and social care professionals. The current mark was chosen because feedback suggested that the quality mark conveyed a sense of authority and would therefore provide assurance when searching for quality information. When assessing information the committee will use the following process:

The Information Standard looks at processes and, in that respect, is similar to schemes such as 'Fair Trade'. The organisation's process for developing information will be assessed rather than individual pieces of information. The assessment will evaluate elements like the organisation's processes for making sure information produced is consistent with latest clinical evidence or their process for involving information users. (DoH, 2009)

Guidance notes regarding identifying, searching and referencing information notes are set out for the production of health and social care information. Figure 3.8 helps to demonstrate the guidance.

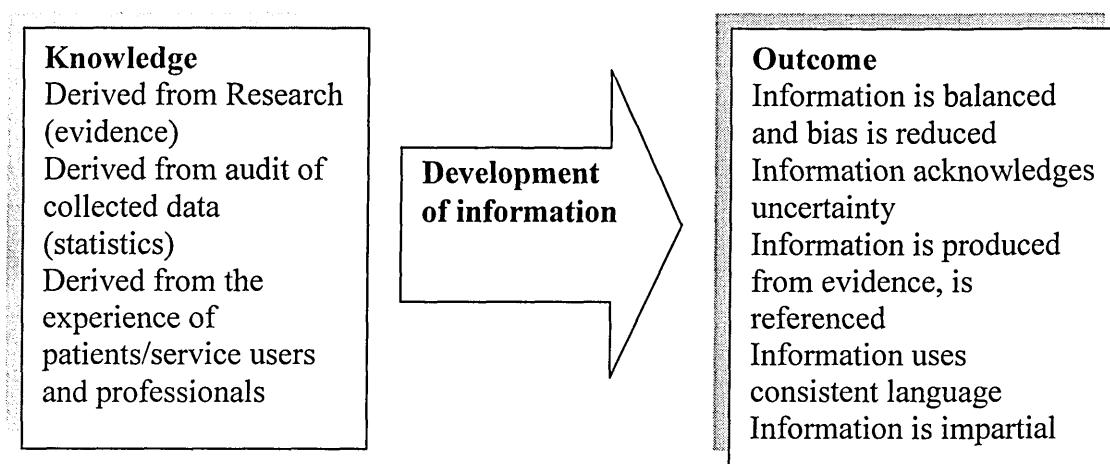


Figure 3.8 – The Information Standard's guidance.

The information standard acknowledges the experience of health and social care professionals as well as the service user or patient. This acknowledgement is crucial to support groups with regards to local newsletters and also lifestyle magazines.

3.9.4 Psychosocial Support

Studies by both Voerman et al (2007) and Grande et al (2006) indicate that psychosocial variables may influence support group membership (figure 3.9, page 145). Participants in the Grande et al (2006) study believed that group membership would lead to feelings of belonging. Participants of the study also reported that the decision to join was to some extent influenced by their existing support network which included various people such as medical professionals as well as families and partners (Grande et al 2006).

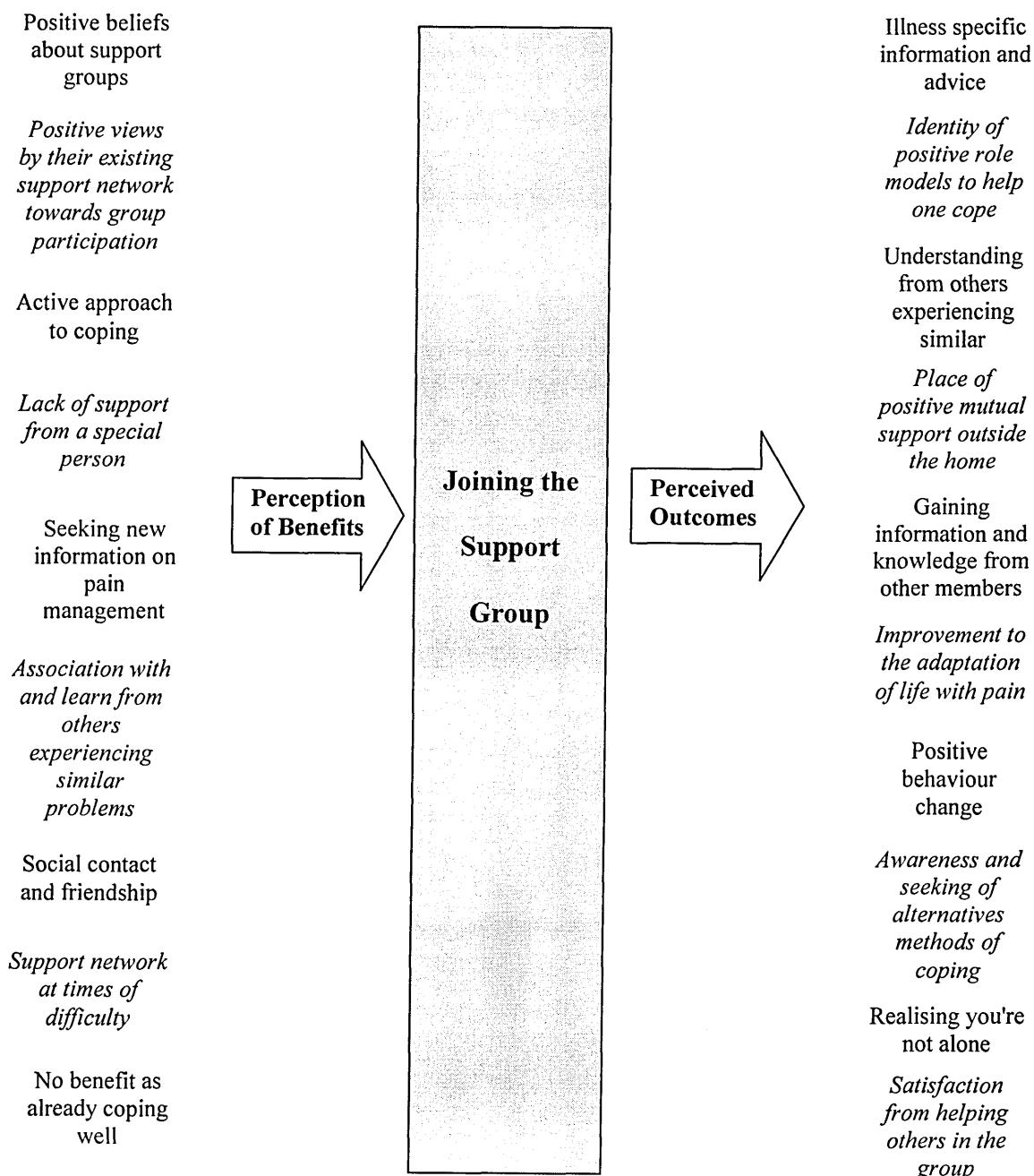


Figure 3.9: The psychosocial variables and perceived outcomes of support group participation (Subramaniam et al, 1999; Grande et al; 2006)

The psychosocial wellbeing of group membership includes meeting others with a similar diagnosis and experiences (Cooper and Burnside 1996; Charlton and Barlow 2002; Purk 2004; Munn-Giddings and McVicar 2006). However, to what extent psychosocial factors influence decisions to join are mixed within the literature. Cooper and Burnside (1996) report that with chronic illness there are key psychosocial issues that need to be addressed. Cooper and Burnside (1996) also report that there are considerable benefits to adding the psychosocial support aspect of care through a group. They suggest that support groups should be open rather than closed. An open group is one that constantly takes new members and unlike closed groups does not run for a fixed time period only. This open aspect had additional benefits for group members in the Cooper and Burnside (1996) study. Firstly, the open aspect of the group helped new members establish role models in the early stages of their illness. Secondly, the open group aspect allowed members flexibility such as allowing members to attend the group at varying time periods post injury.

Schwartz and Sendor (1999) describe altruism and benevolence as positive traits in individuals. They report that the impact that these characteristics have on physical and psychosocial well being, has not been widely investigated. Schwartz and Sendor (1999) explored the impact that helping others had on the physical and psychosocial wellbeing of the provider. Using a randomised trial approach lay support group members were trained to listen actively and provide compassionate, unconditional positive regard to others with the same chronic illness. The findings showed that those who were trained had pronounced improvement on confidence, self awareness, self esteem, depression and role functioning.

Content analysis of the transcripts of focus groups revealed that participants articulated a sense of dramatic change in their lives. This change was reported in terms of how they thought about themselves and in how they related to others. Although Helgeson and Gottlieb (2000) agree that peer support groups do foster a process of mutual help and this can be a source of increased self esteem. They identify that there are two difficulties with this process. Firstly members of the group may provide information to one another that may be harmful. Secondly not all group members will view helping others positively and may find it a burden. This is in contrast to Subramaniam et al (1999) who reported that members of their group identified satisfaction with helping others.

According to Victor et al (2005) loneliness is still conceptualised by many including older adults as an age specific problem. Loneliness as a factor for joining a support groups is more complex than it appears. According to Subramaniam et al (1999) the participants of their study identified an increase in social contacts and friendship as a major reason for joining the chronic pain support group. Adamsen and Rasmussen (2001) also report that a networking function is particularly pronounced in groups that include the disabled and those with chronic illnesses.

In the Subramaniam et al (1999) study participants felt the need to increase their social network despite having relatives living by. Further, the majority of the study participants thought that they lacked adequate support from their existing social network. They reported that it was particularly noticeable when they required support for pain related problems. Participants felt that their chronic pain was poorly understood by close family and friends. This manifested itself in two ways; participants felt a

genuine discomfort when communicating about their pain to those in their existing social network. Secondly, less than half of the participants reported the ease of getting pain related support from their existing social network. According to Subramaniam et al (1999) only one of the participants identified a family member as providing pain support.

For the remainder of the participants' medical staff, pain management clinic staff, counsellors or non-family friends were the main source of pain related support. However Subramaniam et al (1999) suggest that there is a mixed perception of support between participants and their existing social networks. This they report is particularly the case with the participants' partners. The partners believed that their major role was giving support. These support activities were reported by the partners as listening, helping and keeping life as close to *normal* as possible. The issue of perceived support was central to how the participants viewed the group's purpose. When interviewed initially there was a consensus amongst participants that the group should act as a support network. This support network would be available at times of particular difficulty. Also a minority in the initial interview felt that group should act as a discussion forum. Discussion, they felt would revolve around individual pain problems and past treatments. These perceptions of group purpose were reported by Subramaniam et al (1999) as problematic. Like Carlsen (2003), Subramaniam et al (1999) also found that to resolve these issues was reported as particularly time consuming.

Munn-Giddings and McVicar (2006) reported loneliness as stemming from perceived diminishing support was also identified as a factor for joining support groups. The diminishing support was described as being from an individual's usual social network. Like Subramaniam et al (1999), Munn-Giddings and McVicar (2006) reported similar findings. Examples of this were that diminishing support was consistently expressed as close friends and family not being able to cope. Other examples of the social demise were given as their support network not knowing how to offer assistance.

However Munn-Giddings and McVicar (2006) also found that these perceptions were coupled with a feeling that it was not possible for others who did not share their experiences to understand. Munn-Giddings and McVicar (2006), like Subramaniam et al (1999) reported that the participants of the study did have both family and professional support. Munn-Giddings and McVicar (2006) additionally report that there was a belief however that there was something unique and particular to gain from being with others in a similar situation. Helgeson and Gottlieb (2000) warn that this can have negative connotations such as an increase in stigma and isolation. They also suggest that this can have a negative effect on individuals existing natural network. To overcome this potential harm, Helgeson and Gottlieb (2000) suggest that family members should also be allowed access to support group meetings. In contrast Munn-Giddings and McVicar (2006) believe that the uniqueness of being with others in similar situations can manifest itself into the development reciprocal peer relations.

3.9.5 Helper-therapy Principle

Riessman (1965) formalised the notion of a reciprocal peer relationship as *helper-therapy principle*. Robson et al (1999) reported that the helper-therapy principle is the central premise of support groups. Furthermore Robson et al (1999) believes that providing help can have a positive impact on an individual. These positives are described as increasing feelings of competence, equality, social usefulness, independence as well as social value. Robson et al (1999) also suggests that providing help to others allows individuals to view themselves as having strengths as well as needs. This provides opportunities to take on new roles and responsibilities in a safe environment.

3.9.6 Motivational Determinates

Support groups have been identified as a form of self management (Hatzidimitriadou 2002) motivational issues may also be central to joining a support group (Subramaniam et al 1999). Participants in Subramaniam et al (1999) study demonstrated an adaptable approach to managing their pain. They described using a number of alternate approaches with mixed satisfactory results. The participants also used a variety of coping techniques including exercise programmes, acupressure, relaxation, pool activities and walking. Others described using pacing and cognitive strategies as distraction from their chronic pain. What the results of the participants' profiles suggest is two things. Firstly, the participants are already motivated in actively managing their pain and secondly the support group was adjunct to this management.

3.9.7 Previous Support Group Experience

Munn-Giddings and McVicar (2006) and Voerman et al (2007) found that previous experience of the benefits of support group membership was a determinate to joining. The participants without prior support group experience described joining a group as a very difficult step especially if the group was established (Munn-Giddings and McVicar 2006). This issue was also identified by Subramaniam et al (1999); in response the group addressed this issue with the use of an *ice breaker*. The icebreaker began with the statement "*the worst and best thing that has happened to me since the last meeting*". Participants were given 2 minutes to tell the group. The activity worked well to encourage participation by all attendees. It was felt that it strengthened social relations within the group. It was also an opportunity for participants to vent concerns. The ice breaker was also used to enhance the focus on positive issues and achievements.

3.9.8 Personal and Situational Factors

Personal and situational factors according to Hildingh and Fridlund (2001) are an interesting factor. They report that it is difficult to discern which of these factors are of importance for social support seeking in support groups. Hildingh and Fridlund (2001) found was that information about support groups given by healthcare professionals resulted in a relatively high figure of participation. This was also reflected in the earlier study by Cooper and Burnside (1996). Here the support group had a take up rate of fifty percent. Potential members of the group were sourced in the occupational therapy outpatients department of a regional burns unit in the North of England.

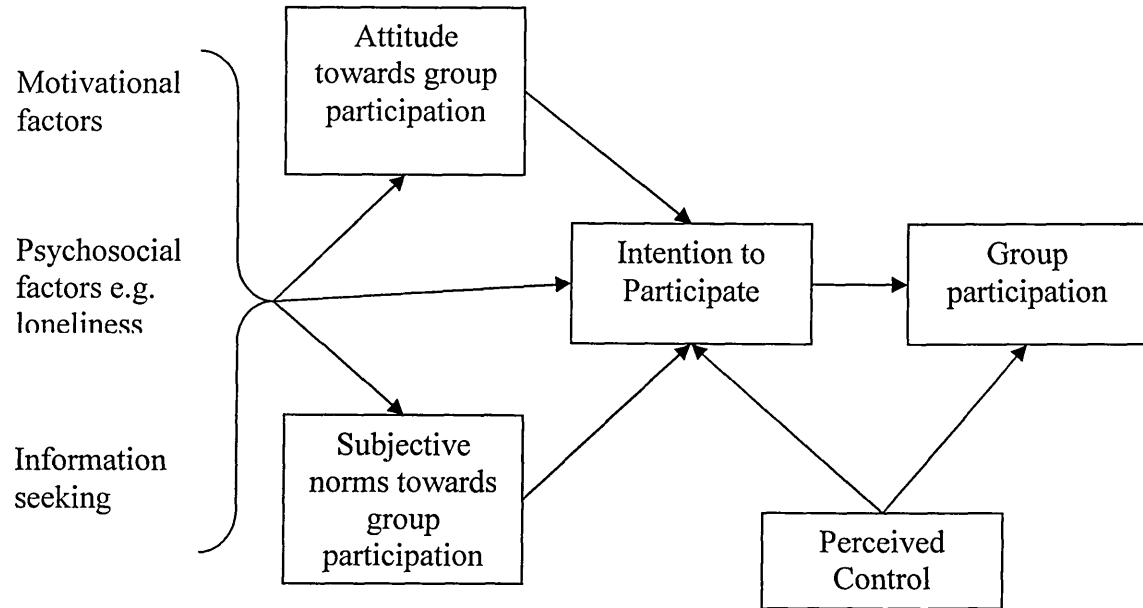


Figure 3.10 Determining factors regarding support group participation modified from Voerman et al (2007)

Summary

In this section of the chapter I have reported on the determining factors which may contribute to motivating an individual experiencing chronic pain becoming a member of a support group. Social support is reported in the literature as being a primary issue, this is not necessarily a response to a reduced or diminished existing network as Subramaniam et al (1999) identified in their study. The need to be with people who are experiencing similar challenges and issues could impact on the outcome of pain severity and adaptive approaches to self management as Langford et al (1997) have reported.

The need for informational support is also reported in the Subramaniam et al (1999) study, here group participants identified that information from health professionals and other speakers was useful, of real benefit was information gained from talking to individual group members.

3.10 Benefits of Support Group Membership

Throughout the literature it is acknowledged that support groups can provide an opportunity for people with a common problem to come together (Subramaniam et al 1999; Bludau-Scordo 2001; Munn-Giddings and McVicar 2006; Butow et al 2007). The main body of the limited support group literature is concerned with group helping mechanisms and individual benefits from group participation (Hatzidimitriadou, 2002). Davidson et al (2000) describes the support group concept as stemming from the assertion that people facing a similar challenge can help each other simply by coming together. This can instil a sense of hope, altruism and empathy along with a sense of belonging and universality (Munn-Giddings and McVicar 2006; Butow et al 2007). They can share their experiences and concerns (Subramaniam et al 1999). In opposition to more formal pain management groups such as the Expert Patient Programme they can learn in context that is controlled by the participants (Subramaniam et al 1999; Grande et al. 2006).

Additionally, the literature identifies that participants in support groups gain personal, interpersonal and collective benefits. These include improved self esteem, self confidence and mutual support. There is also evidence of sharing coping strategies as well as an expanded world view (Munn-Giddings and McVicar 2006).

The groups can be a very effective source of support when people have trouble gaining and avoiding unhelpful interactions (Savelkoul and De Witte 2004) which were identified as *adaptive* and *maladaptive* strategies (Jensen et al 2003). Other group members can act as positive role model for the individual (Grande et al, 2006) which is similar to the more formal management programmes such as the Expert Patient Programme and Challenging Arthritis.

Sharing information and coping that is not available from family, friends and health professionals can also be experienced (Grande et al. 2006) which help address issues of loneliness reported in Chapter Two (e.g. Hollywood 2007). The group requires little or no professional input (Subramaniam 1999; Grande et al. 2006).

The use of support groups is another strategy for self management and support seeking (Hatzidimitriadou 2002; Hildingh and Fridlund 2004; Savelkoul and DeWitte 2004).

There is a suggestion that support groups may provide valuable social support (Damen et al 2000; Savelkoul and DeWitte 2004; Dibb and Yardley 2006). The members' interpret support groups as safe places where people find support and understanding (Hatzidimitriadou, 2002).

Group members acknowledge and exchange experiential knowledge towards successful management with their common problem and empowerment is an important outcome of their participation in such groups (Hatzidimitriadou, 2002).

3.10.1 Social Comparisons

Persons develop their self concept by comparing themselves to others in their chosen reference group (Langford et al, 1997). This context of social comparison is an important process in the development of self-concept (Langford et al, 1997). Social comparison also enhances coping abilities, emotional adjustment, self esteem and psychological wellbeing (Festinger, 1954). Social comparison theory was first recognised by Festinger (1954). The theory postulates that social behaviours can be predicted. This is largely based on the assumption that individuals seek to have and maintain a sense of normalcy and accuracy about their worlds (Davidson et al 2000). Davidson et al (2000) describes illness support groups as nothing more than venues for social comparison. In the social support literature Langford et al (1997) recognises that social comparison may not be successful in the development of self concept without the process of social exchange. The importance of social exchange is evident in the definition of social support by House (1981) amongst others. Tilden and Gyalen (1987) propose that social exchange theory is like a credit and debit system where an exchange of mutually rewarding activities in which the receipt of rewards is contingent on favours returned.

Festinger (1954) predicts that in times of uncertainty group behaviours would increase as individuals seek the opinions of others on how they should be thinking and feeling. Additionally Festinger (1954) describes social comparison as occurring between similar individuals or individuals with similar problems. Dibb and Yardley (2006) remind us that support groups consist of such people.

Davidson et al (2000) also add that social comparison is intrinsic to the healthcare setting. In this setting anxiety levels are often high and educational information when available may not come in the form that is understood by the individual. The results of diagnosis, treatment and side effects of medications prompt individuals to talk to others facing similar situations.

Wills (1981) further added to the social comparison theory by suggesting the existence of downward comparison. Downward comparison is made with a person who is doing less well. According to Wills (1981) this will initiate a positive effect as it increases self esteem. Conversely Taylor and Lobel (1989) believe that upward comparisons with a person who is better off will offer individuals hope. However Dibb and Yardley (2006) now suggest that it is dependent on the individualised interpretation of the situation. An example of this is given as an individual who observes people in a similar situation but who they interpret as better off than themselves. This can affect the observer in two ways. Firstly they could feel optimistic that they could be like that too. Conversely they could feel pessimistic if they believe that they can never end up like that person. Equally according to Dibb and Yardley (2006) downward comparison could result in the individual feeling lucky that they are not in the same situation or anxious because they may be in a similar situation one day.

Dibb and Yardley (2006) add that applying this model to support groups would clearly indicate that there could be positive and negative effects from social comparison. They further suggest that there could be potential issues with social comparison in support groups that was not recognised in earlier literature. The primary issue they give is that

there is no control within the groups over what type of comparison is made. Nor is there control over the interpretation of the comparison. Following from this Dibb and Yardley (2006) UK based study asked how social comparison within a support group influences adjustment to chronic illness. In order to answer the question they developed a theoretical model showing the hypothesised effects of the variables believed to influence adjustments to illness (figure 3.11).

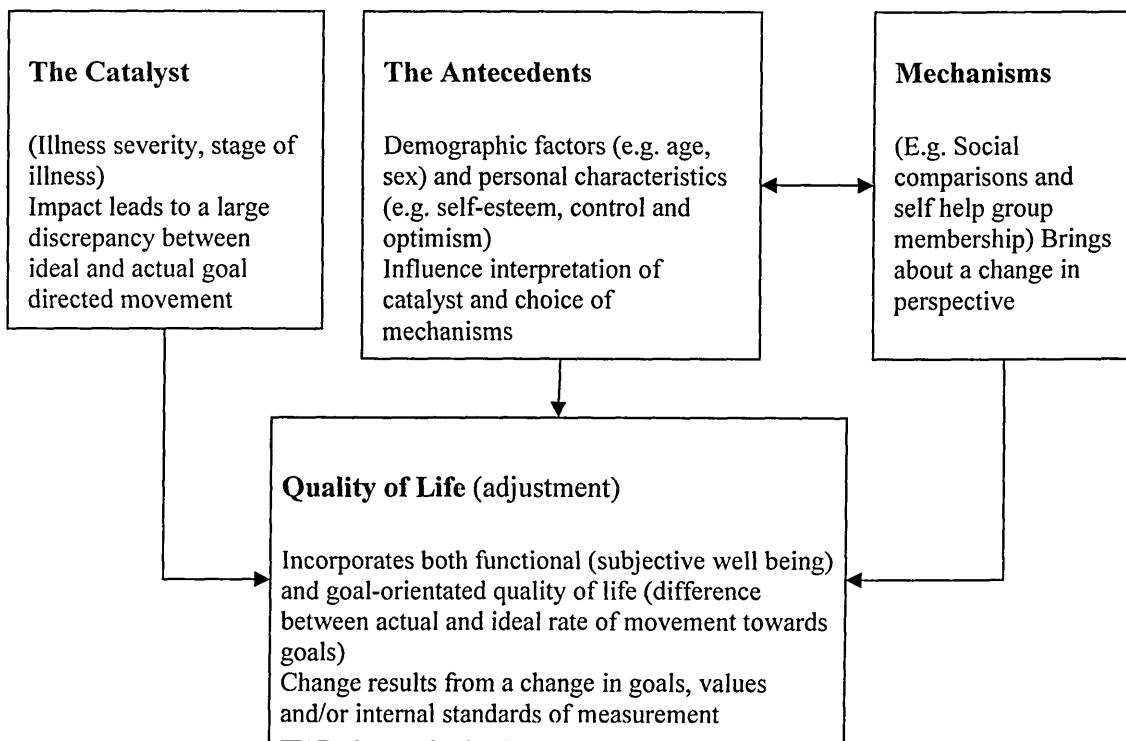


Figure 3.11. Hypothesised effects of the variables believed to influence adjustment to illness (Dibb and Yardley 2006)

Dibb and Yardley (2006) based this model on control process theory. They describe control process theory as a self regulation model that proposes that all behaviour is goal directed. This model was originally described by Carver and Scheier (1990, 2000). Dibb and Yardley (2006) describe the self regulation model as using a feedback loop. The feedback loop is used to measure the ideal and actual rate of progression towards an

individual's goal. The ideal and actual rates are then compared in order to produce affect. Dibb and Yardley (2006) further clarify by explaining that by moving faster than expected towards positive goals results in positive effect. In contrast to moving slower than expected towards positive goals results in negative effect.

In their study, Dibb and Yardley (2006) used the participants' perceptions of how quickly they were moving towards or away from their goals as a measure of adjustment to chronic illness. Measurements via questionnaire were administered at baseline and at ten month follow up. The questionnaires were defined for their study as functional and goal-orientated quality of life. Additionally at baseline participants also completed measures of predictor variables. The predictor variables are shown in the model in figure 3.11 (page 157) and are the catalyst, the antecedents and mechanisms. Dibb and Yardley (2006) further explain the subheadings.

The catalyst is defined as the severity of the symptoms of the illness, in this case Mènière's disease. The antecedents are age, sex, living circumstances, duration of the membership of the support group, self esteem, optimism and perceived control over the illness. The mechanisms are the social comparisons within the support group. The cross-sectional results of the survey of the 349 members of the support group answered the research question. It was shown that positive social comparison was associated with better adjustment. Negative social comparison was shown to be associated with worse adjustment. However, it was also reported that the greater levels of social comparison at baseline were associated with deteriorating quality of life over the 10 month follow up period. Dibb and Yardley (2006) conclude that their findings have potential relevance to

the activities of support groups. The results suggest that in some circumstances that social comparison within a support group could be unhelpful. Dibb and Yardley (2006) offer a solution to this potential problem. They suggest that sharing stories within the group of people who have moved from poor life quality to a more improved quality of life may help. This is especially the case for group members who are currently struggling with their illness to identify with an upward comparison. Editors of support group newsletter should if printing negative accounts of members' experiences suggest positive coping strategies.

3.11 Online Support Groups

The importance of support groups is reflected in their existence today as well as their evolution. The literature search of online support groups resulted in 500 papers focusing on internet based or online groups. This technological evolution in social support could help to explain the limited literature of face to face groups. There were no studies that compared online and face to face support groups and this would be worth considering for future studies. There is consensus of opinion amongst the majority of the online studies that the internet is a useful tool for support groups (Fox, 2001).

In his study Fox (2001) reports that the internet can make a positive contribution to educational support through the broadcasting of information as well as a means of communication between members. Despite the rise in the popularity of online groups the merit of face to face support groups cannot be ignored. Future studies may report that individuals may use a combination of both group types. The study and subsequent reporting of the activities of online support groups, has issues that the study of face to face support groups has previously addressed such as ethical committee approval. These

include ethical issues which include data protection and data ownership. In addition to ethical issues there are also reports in the literature that internet usage of the population of this current study is described as mundane (Selwyn et al 2003; Selwyn, 2004).

3.11.1 Ethical issues

Ethical debates surrounding the use of internet data and internet based research continue (Haigh and Jones 2005). A literature search using the term 'internet and ethics' was used in the British Nursing Index (Ovid) 1994 - 2008 resulted in 544 papers. Location of potential study participants was also pertinent in the search and as consequence studies that reported ethical issues outside the European Union were excluded. This is because citizens of the European Union are protected by the most stringent levels of data protection (Haigh and Jones 2005). This data protection is in contrast to the United States of America and elsewhere. The level of security is due to the European Union Data Protection Directive (1995). Also excluded were studies that were more than 5 years old. Exclusion of these studies is due in part to the pace of change of the debate of the use of data from the internet (Haigh and Jones 2005). Haigh and Jones (2005) report that internet research ethical issues do not differ from real world research.

Concepts such as confidentiality, privacy and consent from participants as well protection from harm still have relevance to online groups. Haigh and Jones (2005) report that it is a myth that the contents of the internet are copyright free and use of online data can create difficulties in obtaining ethical approval. There is currently a mixed response from ethics committees and a lack of understanding regarding the complexities of ethical considerations (Haigh and Jones, 2005). In response social sciences are in the process of trying to address the complexities of internet research,

they also recommend that nurse education and the nursing profession draw upon their experiences as well as contribute to the debate across the disciplines.

The majority of those accessing online support groups primarily do so to obtain health information or educational support (McMullan, 2006). Additionally, McMullan (2006) reported that internet information can improve an individual's understanding of their medical condition as well as their self efficacy. A more informed individual can become empowered to make health decisions and talk to their physicians. This can have an effect on the doctor patient relationship and is reported by McMullan (2006) as resulting in a shift in the role of the patient from a passive recipient to a more active consumer. However the literature regarding online support group does not offer anything significantly different from face to face support groups. The exception to this is the convenience due in part to the removal of geographical and transportation barriers (McMullan, 2006). This convenience could be pertinent to older adults and others with limited mobility, access to transportation and fear of leaving the home on dark evenings. However there is also the disadvantage of lack of physical support (McMullan, 2006).

3.11.2 Internet Usage by Older Adults

At present the use of the internet by older adults is described as mundane (Selwyn et al, 2003; Selwyn, 2004). Richardson et al (2005) explains that the vast majority of older adults have not had the opportunity to learn about and use computers. There is also a suggestion that older adults are far less interested in computers than younger adults (Richardson et al 2005). These studies reported the use by older adult's (aged 61+) of information and communication technology in everyday life. Despite previous studies Selwyn et al (2003) and Selwyn (2004) data did not show a substantially higher

prevalence of the use of Information Technology (IT) amongst older adults. Selwyn et al (2003) and Selwyn (2004) believe that the pace of change reported in previous studies has been overstated.

However, future studies of older adults will include those who are currently 41 - 60 years old (Selwyn et al 2003). This cohort will bring with them higher levels of computer skills (Selwyn et al 2003) due to the normalisation of computer use in the home and in the work place. The Selwyn et al (2003) study also reports that currently those aged 61+ were the age group that used computers and the internet the least.

Selwyn et al (2003) offer possible reasons for this. It is assumed that many older adults left their work place prior to the instillation and normalised use of computers. Older adults unlike their younger counterparts rarely have children who are in full time education living with them. Adults who have school aged children have been shown to be more aware of the use of computer technology (Selwyn et al 2003). Also the majority of older adults have left full time education a number of years ago. However Selwyn et al (2003) also reported that forty percent of the older adult respondents had access to computers at home. It was also found that around 36% of respondents accessed computer technology at a public site, such as a library. Interestingly only 22.4% of the older adult respondents had used the computer during the past twelve months. Only 15.1% of respondents had accessed the internet in the last twelve months. What the respondents used information technology for was mixed. The majority who had access to a computer used it for offline administrative purposes such as writing letters and editing documents. When using the internet it was reported that the most frequent use by the respondents was for sending and reading e-mails. They also used the

internet to gather product information related to the home. A small percentage also reported downloading software, music, films or images.

The results of the Selwyn (2003) study demonstrated that there was little use by older adults of the internet. Although arguably this study only offers us a 'snapshot' of information technology (IT) use by older adults. Selwyn et al (2003) describe their study as capturing a moment in time. Selwyn et al (2003) believe that the relevance of any study of society's use of technology is limited due to its temporary nature. However it is suggested that the next age cohort who will bring with them their experiences of high use of IT. In the results of the Selwyn (2003) study there were no reports of the use of the internet for illness support or information by the respondents. As Selwyn et al (2003) conclude their data shows that the use of IT by older adults is more mundane.

Summary

According to the literature current internet use by older adults is described as mundane. This aspect of limited use of information technology by older adults, as well as ethical issues which are currently being debated has resulted in this current study focusing on face to face support groups.

3.12 Chapter Summary

In this chapter I have identified from the literature an operational definition for the support groups to be sampled in this current study. Additionally I have also reported on the difficulty of identifying an operational definition for social support. In the support group literature social and informational support are defined separately even though the social support literature suggests that informational support is one of the four

components of social support. The review of the literature has also suggested that the number of support groups in the United Kingdom is increasing. This increase is also being observed in online support groups, even though these are not the focus of this study. In the literature only one chronic pain support group paper was identified and the focus was not older adults. There were components of this paper which have helped influence this current study. I have also identified that there are other groups for older adults that provide support which are not intended to be chronic pain focused such as the exercise and line dancing groups as well as less formal gathering in fast food restaurants. This suggests that illness may not be a motivating factor for joining a support group. In response I have explored the literature to identify motivating factors to join a support group.

There remains gaps in this aspect of the literature including; the location of the individual within their chronic pain trajectory of when participation in a support group may have the most impact, the routes people take to becoming members is not explored in detail an example is that is the recommendation by a healthcare professional a mutually agreed decision. There is also underreporting of two of the four components social support (Langford et al, 1997) with instrumental and appraisal support not being mentioned. The literature also identifies that social and informational needs are primary motivating factors in joining a support group, which suggests self management activities but this is not explicitly explored in detail in the reviewed literature. Finally the provision and type and how chronic pain is broadcasted in groups is also not reported.

This chapter has also explored the literature relating to self management programmes including the Expert Patient Programme and Challenging Arthritis. The results of the studies suggest that the outcome from participation is generally positive. However this may be a reflection of the length of time an individual has experienced their chronic pain. This may have an impact on locating a point in a persons' trajectory which could motivate them to join a support group. In addition the inflexibility of attending meetings and the time limited length of chronic illness programmes may not be seen as a positive attribute by someone seeking support.

Chapter 4

Section 1 – Aims and Research Questions

The first section of this chapter will discuss the theoretical framework for this current study. This framework informs the research questions and consequently the aims of the study. The framework also developed the subsidiary research questions and aims. The second section of this chapter explores the methodological approaches available to me and the reason for choosing ethnography for this current study. The role of the ethnographer is also discussed.

4.1 Theoretical Framework

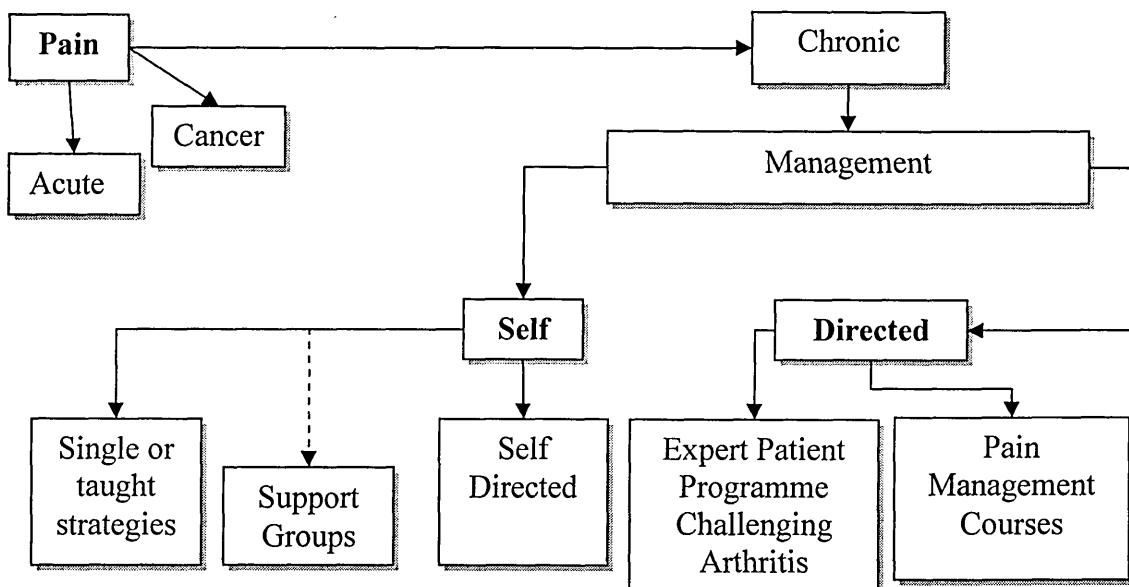


Figure 4.1 the theoretical framework

The theoretical framework (figure 4.1) was developed following the review of the chronic pain and support group literature. The complexities of chronic pain and the challenges to its management are the focus of the theoretical framework. I have divided the management of chronic pain into two strategies which include directed and self.

Directed management strategies include courses that are hosted by formal organisations such as the National Health Service (NHS) as well as charitable organisations such as Arthritis Care. These include pain management courses and the Expert Patient Programme (EPP) or Challenging Arthritis (CA) and are usually curricular based activities. Attendance at these courses is for a set time period which in the case of the EPP is 2 hourly weekly sessions for 6 weeks. In contrast ‘the self’ approach to management are strategies that are adopted by the individual through reading, recognising their capabilities and adopting a routine which is appropriate to their circumstances. In addition, the self approach includes joining a support group which is different from the EPP or CA primarily because support groups are open and the route to joining the groups can be multiple rather not just referral. Hatzidimitriadou (2002) reported that support groups are a form of self management and I would like to investigate this further.

In chapter two I described the symptoms of chronic pain that have been identified as particularly bothersome to older adults and its impact on their quality of life. These symptoms can contribute to the prevention of effective self management strategies being adopted. These symptoms were identified in Chapter 2 and include isolation, anxiety, learned helplessness and depression. The symptoms of chronic pain impact on the biomedical, psychological and social wellbeing of an individual. Effective management of these symptoms can help the individual to maintain some quality of life and reduce the impact on their psychological and social well being. Additionally management activities that are utilised by and benefit the individual can impact on their self confidence and coping.

The review of the chronic pain literature reported that social support is of particular importance to older adults. This is due in part to shrinkage of existing social networks through death, limited mobility due to pain or other medicalised problems as well as family moving away. Older adults also report that they do not always report their pain problems to those in their existing social networks due to perceptions that they could be misunderstood or deemed a burden. Older adults do recognise that the ideal for them is to maintain their independence as well as regain some life quality.

In chapter three I reviewed the support group literature which suggests that for the majority of members' social support (Hildingh and Fridlund, 2001) and informational support (Bludau-Scordo, 2001; Purk, 2004) are the primary motivating factors in joining a support group. This suggests elements of self management by the motivated individual but this is not explicitly expressed in the reviewed literature. The motivation for joining support groups is not explored in detail, for example is there more than one factor, do these factors change overtime? The support group literature also reports on the routes people take to becoming members but this is not explored in detail, for example if the group is recommended by a healthcare professional had the individual considered joining a group before? Finally the provision, type and how chronic pain information is broadcasted within the groups is not reported in great detail in the reviewed support group studies.

In their strategy document Self Care (DoH, 2001) the UK government recognises the work of local support groups and highlights the importance of local access to self care information and support networks that these groups can offer (DoH, 2001). However

they appear to overlook the purpose of support groups by suggesting that they are useful for sourcing potential candidates for self management programmes such as the Expert Patient Programme.

The self management of older adults who are members of support groups is the focus of this current study and within this is single or taught strategies and support group approaches. Single or taught strategies refers to an individual's approach to pain issues or self-taught strategies, self directed approaches to pain management in this current study also includes support groups. This current study will record the pain accounts of older adults and through analysis establish where in their chronic pain experience motivation to join a support group could occur. However there is a note of caution here in that I am not seeking an exact time scale of when a person is motivated to join a support group e.g. three years post diagnosis. Chronic pain is an individual and subjective experience but there may be a pattern that emerges from the collected data which suggests that support groups are suitable for people who have been discharged from or reduced their contact with the formal healthcare system and therefore may not be beneficial for the newly diagnosed etc. The purpose of support groups from the perspective of older adults will then be explored focusing on the social support provided by these groups.

4.1 The Research Question

The aim of this study is to explore, examine and observe the experiences of older adults participating in support groups for non-cancer pain.

Main Research Question

- What is the purpose of support groups from the perspective of older adult group members experiencing chronic pain?

Subsidiary Questions

- What motivated individuals to participate in the group?
 - The purpose of this question is to determine the motivation and routes to joining the group e.g. advertising, healthcare professionals
- What benefits do older adults participants perceive from taking part in support groups?
 - The purpose of this question is to explore the groups' provision of the four components of social support (Langford et al, 1997) which include informational, emotional, appraisal and instrumental.
- What impact does the support group have on the self management activities of older adult group members?
 - Techniques that are discussed in the group meetings will also be recorded and analysed (guest speakers, discussions), as well as in the accounts of older adult group participants
- When in their chronic pain trajectory do older adults become group members?

4.2 Operational Definitions

In this current study there are a number of operational definitions including older adults, support groups and social support that need to be presented. This current study will use the socially-constructed definition of old age defined in the National Service Framework for Older People (DoH, 2001). For the purpose of this study older adults will include those who are aged 55 years or older. The groups to be sampled for this current study will need to meet the following criteria; 1) groups that are peer led 2) groups with no or limited professional input 3) groups that meet regularly but do not require regular attendance 4) groups that do not have a limited length of membership.

The review of the social support literature suggested there is little consensus regarding a theoretical and operational definition for social support (Faulkner and Davies, 2005). However, Langford et al (1997) concluded after a review of the literature that social support relates to one or any combination of four broad components (Figure 3.5 page 133). The operational definition of social support for this current study is any action that includes instrumental, informational, emotional and appraisal support. These components are described further in chapter 3 page 132.

Section 2 – Methodology

My initial curiosity for this research was stimulated by previous experience of support groups and awareness of my limited knowledge of their purpose. As a nurse I often suggested that an individual joined a support group to obtain further information about their particular long-term health issues. I made people aware of support groups without fully understanding the benefits as well as the negative aspects of such an intervention. There was also the perception that support groups were an excellent venue for individuals who requested further information beyond the standard in the formal healthcare setting. Therefore the exploratory nature of this current study was the primary reason for selecting qualitative methodology. The limited support group literature was secondary in the choice of methodology for this current study. The intention of this chapter is to identify the methodological approaches available when studying groups or cultures and I will discuss the chosen ethnographic approach. The review of the limited support group literature identified gaps within existing knowledge. These gaps have been discussed in the previous section.

4.3 Methods Available

Ethnography is the study of groups and or culture but there are other qualitative methods that were considered for this current study. These include phenomenology, a case study approach, or grounded theory. There was a dilemma regarding my professional background as the support group literature emphasised the minimal professional input, which defines support groups, this suggested that I needed to be aware of my own interpretative authority.

Phenomenology is the study of the lived experience of individuals and is reported to be influential in continental Europe rather than the United Kingdom or other English speaking locations (Harré, 2006; Silverman, 2006). It is reported to have played a major role in the development of ideas of the social construction of reality. The exploration of the lived experience of the older adult participant would have been an ideal approach for this current study. However I also wanted to observe a support group over a period of time and explore their function as a participant observer. Phenomenology has similarities with ethnography in that they are both exploratory and use the researcher as the data collection instrument (Maggs-Rapport, 2000). In addition they both use interviews, both use a combination of open ended and structured questioning methods and both look for meaning in the narratives (Maggs-Rapport, 2000). There is however fundamental differences in that ethnography concentrates on the individual or shared views and values of a particular culture and aims to describe the cultural knowledge of the participants (Maggs-Rapport, 2000). In contrast interpretive phenomenology tries to uncover concealed meaning in the phenomenon, embedded in the words of the narrative (Sorrell and Redmond, 1995).

A case study is an approach that uses in-depth investigation of one or more examples of a current social phenomenon, utilising a variety of sources of data (Keddie, 2006). A ‘case’ can be an individual person, an event, a group, organisation or institution (Keddie, 2006). This approach would be of use in this current study, the case could be the group or a new member attending the group with the investigation revolving around the experiences of the individual over a predefined time period.

However as Keddie (2006) reports the main criticism of the case study method is that in most circumstances the individual cases are not sufficiently representative to permit generalisation to other situations. Keddie's (2006) remarks about a case study approach were pertinent in the decision to exclude a case study approach. As there is limited literature regarding older adults in chronic pain support groups I felt that I needed a larger sample.

Although grounded theory was initially excluded because it assumes that the researcher approaches a topic without any preconceived conceptual framework and this is formed later entirely by the data (Harding, 2006). I believe that it would have been difficult for me to approach support groups without any preconceived concepts of their function. I developed notions of what support groups offered from my previous experience as a nurse and research associate within the pharmaceutical industry. There were aspects of the grounded theory approach that were deemed important because of the lack of previous studies. The flexibility of strategies for collecting and analysing the data (Charmaz and Mitchell, 2001) was of particular interest. However the decision was made to use schema analysis (Ryan and Bernard, 2003) as it is similar to grounded theory and will be discussed in more detail in Chapter 5 page 221. It was intended that for this current study there would be a pursuit of emergent themes through early data analysis.

Ethnography was chosen because in this stance there is the assumption that personal engagement with the subject is the key to understanding a particular culture, or social setting (Maggs-Rapport, 2000; Hobbs, 2006). Participant observation is the most common component of this methodological approach but interviews are also in the

repertoire of the ethnographer (Hobbs, 2006). The choice of approaching a study using participant observation and interviews produces descriptive data. According to Maggs-Rapport (2000) and Hobbs (2006) description resides at the core of ethnography, however this description is constructed it is the intense meaning of social life from the everyday perspective of group members that is sought. Ethnographic interviewing differs to other qualitative interview studies as Sherman-Heyl (2001) highlights:

"Given that there is a great deal of overlapping terminology in the areas of qualitative research and ethnography, the definition of ethnographic interviewing here will include those projects in which researchers have established respectful, ongoing relationships with their interviewees, including enough rapport for there to be a genuine exchange of views and enough time and openness in the interviews for the interviewees to explore purposefully with the researcher the meanings they place on events in their world." (Page 369)

Therefore a number of factors including time, duration and frequency of contact as well as the quality or emerging relationships helps to distinguish ethnographic interviewing from other types of interview studies. Sheman Heyl (2001) also suggests that ethnographic interviews may empower participants to shape, according to their world views, the questions being asked and possibly even the focus of the research study.

In the initial stages of this current study quantitative approaches such as surveys were considered. The advantage to this approach is that a significant volume of groups can be studied. However in support groups there are a number of issues with regards to the use of a quantitative approach. Questions are raised about this approach in this particular setting. These questions are formulated from the epistemological stance as well as the culture of the groups themselves. Epistemologically very little research has been conducted within the social setting of support groups as was previously commented in chapter three. In chapter three Butow et al (2007) remarked that optimal outcomes can

not always be clear because support groups differ marginally in their content, process and structure. McDermott (2005) also recognises issues with researching support groups but recognises factors that can be researched, these include comparisons of group or individual interventions, severity of problems that bring people to a group, motivation of group members and the social support that was available to them.

The use of a quantitative approach was rejected for this current study because it often lacks *social validity*, which is pertinent to the research of cultures and groups. The literature reports that there is an inability to measure the outcome of chronic illness support groups' membership and this helped to inform the methodological approach of this current study. Finally the differing structures of support groups make it difficult for a comparative study.

4.4 Constructionism

Epistemology is the theory of knowledge embedded in the theoretical perspective and thereby in the methodology. The epistemology of an ethnographic study is constructionism, sometimes referred to as constructivist (Bryman 2008). Crotty (1998) posits that social constructionism is at once realist and relativist. In other words to say that meaningful reality is socially constructed is not to say that it is not real (Crotty 1998). Guba and Lincoln (2005) add that the ontology of constructionism is relativism with local and specific co-constructed realities. According to Crotty (1998) and other writers of qualitative methods, most notably Mason (2002), Creswell (1998) and Hammersley and Atkinson (1995), ethnography sprang from anthropology and anthropological theory, however it has been adopted by symbolic interactionism and adapted to its own purposes. Therefore the theoretical perspective of ethnography

according to Crotty (1998) is symbolic interactionism. The traditional method that is associated with ethnography is participant observation. Mason (2006) argues that because ethnography encompasses such a wide range of perspectives and activities the idea of adhering to an ethnographic position is ridiculous. This, as she adds is because in ethnography there is more than one ethnographic position. As Mason (2006) and others make clear there are other methods that are associated with ethnographic methodology of these interviews and they have a relevance to this current study.

However Mackenzie (1994) posits that the terminology of qualitative research is often confused. Mackenzie (1994) also adds that ethnography is frequently used as a general term for qualitative research, or alternatively as a synonym for other qualitative approaches such as phenomenology interactionism, or grounded theory.

Atkinson et al (2001) describe ethnography as a useful group of methods that has survived and flourished for over a century. They add that the salient reason for this is because it is an appropriate way of collecting data on and in a plethora of social settings. These social settings can be as varied as a psychiatric unit to a police station. Atkinson et al (2001) describe ethnography as being robust and flexible which they attribute to why the method works when studying groups in social settings. According to Hammersley and Atkinson (1995) recent decades have seen an increase in the popularity of ethnography as an approach. Hammersley and Atkinson (1995) suggest that this stems in part from disillusionment with quantitative methods. Quantitative methods have long held the dominant position in most social sciences and in most areas of applied social science. Hammersley and Atkinson (1995) also add that the rise in

popularity of qualitative research has resulted in this methodology being the dominant approach.

The current literature helps us to understand that one of the purposes of support groups is that they are a chance for people with a common problem to come together. This togetherness has the ability to offer mutual support in a non-judgemental supportive environment. However what we do not understand from the current literature includes; Why are people in the groups? What made them decide? What social support and informational support is provided? When do they decide to join the group? Where in chronic pain process do individuals become motivated to access to the groups?

In order to attempt to answer some of the questions that I have generated about groups involves careful choice of a methodology. The obvious choice that was available to me was ethnography. This method is one of the oldest employed in studying a different culture and this is reflected in its anthropological origins. The ontological aspect of my decision making is constructionism which asserts that social phenomena and their meanings are continually being accomplished by social actors (Bryman 2008). This ontological position implies that social phenomena and categories are not only produced through social interaction but that they are in a constant state of revision (Bryman 2008). In other words social constructivist perspective emphasises that meaning-making is central to our perceptions of social reality and our actions in the social world (McDermott 2005). It also suggests that interviewers and interviewees are actively engaged in constructing meaning (Silverman 2006). This approach gives the study a strategic slant with trustworthiness as my overall approach.

4.5 Ethnography

It is recognised in the literature that researchers who have an interest in culture found that traditional sciences were inadequate for their needs (Streubert and Carpenter 1999; Atkinson et al 2001; Bryman 2008). This inadequacy Streubert and Carpenter (1999) describe as leading to the beginnings of ethnography; a means of studying groups of individuals' life style or pattern. Ethnography is quite literally the science of description (graphic) of a group of people and their culture (ethno). Unsurprisingly the origins of ethnography are founded in anthropology (Hammersley and Atkinson 1995; Atkinson et al 2001; Silverman 2004; Bryman 2008). However, ethnography is also one of the oldest qualitative approaches used in nursing research (Oliffe, 2005). Early nurse ethnographers embraced the methods of anthropology (Streubert and Carpenter, 1999). This enabled these pioneers of nursing research to study phenomena that they perceived as being irreducible, unquantifiable, or unable to be made objective. Additionally, Oliffe (2005) reports that ethnography has provided valuable insights into diverse aspects of nursing practice through the ability to describe the patients' illness experience and health behaviours. However early ethnographers have been criticized for hierarchical and undemocratic relationships they had with the participants of their studies (Atkinson and Hammersley 1994). These criticisms have lead to the understanding that the results of ethnography are influenced by a number of factors (Borbasi et al 2005). These influential factors include the researchers cultural differences, their participation in the field as well as their reflections on the data collected (Borbasi et al 2005). The influence of self is now seen as integral to the process of fieldwork and in the construction of ethnographic accounts.

Oliffe (2005) reports that through the use of ethnography in studies it is acknowledged that there is researcher influence on the process of gathering and analysing data. This is very much in contrast to survey questionnaires or quantitative analyses where objectivity is sought. This objectivity has long been acknowledged by ethnographers as unachievable (Pellatt 2003). To further clarify this Pellatt (2003) recognises that ethnographers have been unable to put their knowledge of the social world to one side in order that they may achieve objectivity. The recognition that the researcher is an integral part of the world being studied is termed reflexivity (Carolan 2003; Pellatt 2003) and will be discussed further on page 185.

The characteristics of ethnography are described by Streubert and Carpenter (1999) as being central to the research. They identify six characteristics; the first three could also be claimed by other qualitative methods, the remaining three are exclusive to ethnography (Streubert and Carpenter 1999; Robson 2002) they are presented in table 4.1.

Three characteristics of ethnography that can also be claimed by other qualitative methods:

- Researchers as instrument
- Fieldwork
- Cyclic nature of data collection and analysis

The remaining characteristics that are exclusive to ethnography :

- Focus on culture
- Cultural immersion
- Tension between researcher as researcher and researcher as cultural member (reflexivity)

Table 4.1: the six characteristics of ethnographic research, adapted from Streubert and Carpenter (1999) and Robson (2001)

Streubert and Carpenter (1999) also state that the six characteristics should be considered foundational to ethnographic research.

4.6 History of Ethnography

Wolcott (2001) reports that prior to the past three to four decades very little had been written about field methods. Although according to Streubert and Carpenter (1999) there continues to be much debate about the historical beginnings of ethnography (Malinowski's 1922). What is known and reported in much of the literature is the work of the Chicago School (Streubert and Carpenter 1999; Bryman 2008). Most notably from this school is the salient and much quoted Whyte (1955) study of street corner society in slum areas of Boston in the United States of America. However, it is also reported that ethnography was used prior to the work of the Chicago School. In the colonies of European powers for example, here the culture of the population were contrasted with that of their Western invaders (in this case the cultural authority). Experiences were studied and comparisons were made (Streubert and Carpenter 1999; Atkinson et al 2001). The issue that this form of colonial ethnography has is that the researchers in these particular studies are the voice of authority (Murphy and Dingwall 2001). This authorial voice has immediate effects on the participant's right to self definition; Murphy and Dingwall (2001) refer to this issue as *interpretative authority*. The issue of interpretative authority has poignancy in modern ethnographic studies. Murphy and Dingwall (2001) suggest that feminist researchers in particular have argued for sharing control of interpretation as it is believed to break down the hierarchical relationship between researcher and the researched, thus avoiding the exploitation of participants. This is of particular importance for this current study due to minimal professional input that defines the character of the sampled groups.

Byrne (2001) further describes that the use of ethnography is to describe a culture.

Culture, according to Byrne (2001) has many definitions but usually consists of origins, values, roles, and material items associated with a particular group of people.

Ethnographic research attempts to describe aspects and norms of a cultural group to enhance understanding of the people being studied. Creswell (1998) states that an ethnographic design is chosen when the investigator wants to study behaviours of a culture sharing group. Creswell's (1998) statement is reflected in the research questions and aims on page 170. In the case of this current study the behaviours are the focus and reporting of the provision of support offered by the sampled support groups as well as the format and content of the meetings. The cultural aspect of the sampled groups refers to the collective approaches members have towards their chronic pain and how the group impacts on individual self management activities.

4.7 Inspiration and Influence from Traditional Paradigms

According to Byrne (2001) there are four perspectives of ethnography and these include classical, systemic, interpretative / hermeneutic and critical. Byrne (2001) warns that to a novice reader or evaluator of ethnography these perspectives can seem irrelevant. However to the ethnographer these perspectives should be understood and matched to the research focus. The epistemological basis for ethnography is hermeneutics which has concerns for immersive understanding (Bloor, 2001).

Murphy (2005) suggests that the process of developing as a competent ethnographer involves reversion to a familiar identity in the early stages of the study. Murphy (2005) reached this conclusion when analysing early fieldwork entries during the initial stages

of an ethnographic nursing study. Here it was revealed that the nurse tended to work in the field as a nurse rather than being fully engaged in the role and identity of an ethnographer. Murphy (2005) believes that this reversion to a more familiar identity is a necessary stage in preparing for an ethnographic study and that it should be viewed as a form of work. Like any other form of work there are successions of rules and competencies to be mastered (Murphy 2005). The work by Murphy (2005) helped inform my approach in this current study. In preparing for the ethnographic fieldwork the reversion to a familiar identity was an important stage in engaging with the support group members and potential interview participants. However as I have previously reported the operational definition of the support groups have minimal professional input and this suggests that careful explanations of my professional stance will be needed within the sampled groups e.g. I am not attending the group as a nurse but as a group participant. Although in the literature Borbasi et al (2005) also reports that the transition to ethnographer has been viewed as somewhat easier for nurses as it is for other social researchers. This is because many of the skills that are considered essential to ethnographic work are associated with nursing. These are assumed to include good interviewing and listening skills; astute observation and interpretation on several levels, simultaneously and intentional use of self (Borbasi et al 2005).

Maso (2001) suggests that there is a need for a *settling in* period for the ethnographer. Initially the ethnographer behaves like an unconcerned onlooker who is able to place the culture of the new group competently in an interpretive framework provided by their own culture (Maso, 2001). In order to orient oneself in the new culture it is necessary to know where you stand as an ethnographer although Maso (2001) declares that the

individual cannot know this initially because they do not have a position within the culture of the group to be observed.

4.8 The Roles of the Ethnographer

Prior to describing the methodology used in this study the multiple roles that define ethnographers need to be described. Ethnographic roles are often related to ongoing access and are sometimes referred to as relationships within the field. Figure 4.2 illustrates the four ethnographic participant observer roles.

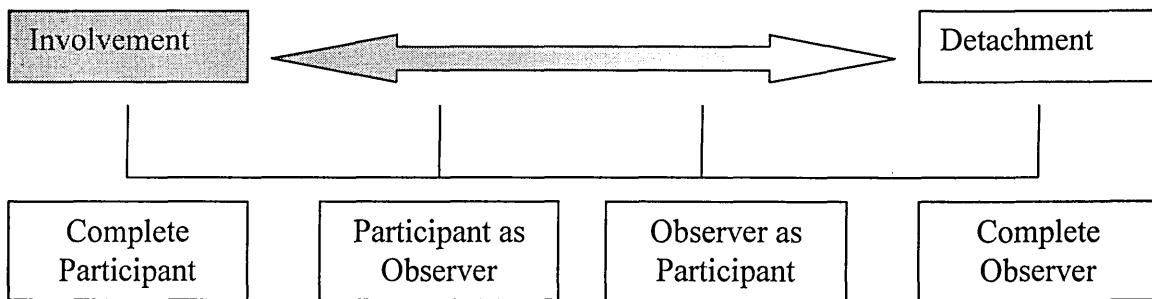


Figure 4.2: Gold's classification of Participant Observer roles (Bryman 2008)

This current study suggests that the participant observer is an appropriate approach to studying the sampled groups. Although in truth ethnography does not necessarily involve role rigidity and a number of ethnographic stances coexist. The role of the participant observer would be beneficial for this study. This is because the ethnographer engages in regular interactions with people and participants within the social setting. The role is overt and its flexibility allows it to be used in open/public or closed settings. Bryman (2008) suggests that the role of a participant as observer does not differ greatly from that of a complete participant. The main difference is that the members of the social setting are aware of the ethnographer's status as a researcher. The decision to

choose the role of participant observer is also in response to an initial need to experience what joining a support group is like for the group participants. Hammersley and Atkinson (1995) report that in the early days of field work the conduct of the ethnographer differs very little from that of any lay person faced with a practical need to make sense of a particular social setting.

The other ethnographic roles were not appropriate for this current study. Bryman (2008) suggests that the role of complete observer means that the researcher does not interact with people. This approach was deemed unsuitable because the sampling and recruitment of individuals for the interviews as well as the group observations involved interaction. The role of the observer as participant was also rejected as this involves the ethnographer being an interviewer only. There is some observation but very little of it involves any participation. Bryman (2008) suggests that this role has been successfully used for ethnographic research on the police. Here the opportunities for genuine participation are few due to considerations of legality and interrupting operational policing.

4.9 Reflexivity

Reflexivity refers to the simultaneously embedded and constitutive character of actions talk and understanding (Atkinson et al, 2001). However, seeking definitions of reflexivity are acknowledged by both Pellatt (2003) and Carolan (2003) as problematic in the nursing world. Pellatt (2003) reports that the definition is varied and further posits that this probably echoes the concept of reflexivity itself, whereas Carolan (2003) believes that the actual term ‘reflexivity’ when applied to nursing remains poorly described. This is despite the proliferation of qualitative research articles that detail self-

reflection and reflective practice (Carolan 2003). In conclusion Carolan (2003) suggest that the term reflexivity is really about how the researcher impacts on the data being gathered and the critical analysis of that role.

It is perhaps therefore unsurprising that reflexivity is the recognition that the researcher is an integral part of the social setting being studied (Pellatt 2003). Carolan (2003) and Pellatt (2003) report that reflexivity enabled them to acknowledge their taken for granted values. Further it also helped Pellatt (2003) to consider how these values impinged on both her research and practice. Allen (2004) however believes that accounts like Pellatt (2003) are undoubtedly insightful but has concerns with regards to the tendency to emphasise psychological introspection over sociological reflexivity. In contrast Carolan (2003) also acknowledged that her clinical background as a midwife influenced her data collection. Additionally she acknowledges that her pro-natalistic stance, which is to encourage parenting, with her personal feminist leanings inspired the feminist component to the methodology used. The feminist component used in the study was further described as being strictly in the pro-femina understanding of the word.

The researcher's perspective is also acknowledged as an important component of the reflexivity of the researcher. The perspectives of the researcher in ethnographic studies are described by Byrne (2001) as *etic* or *emic*. An orientation that is *etic* is a view from the outsider's perspective. An *emic* orientation is from an insider's perspective. Byrne (2001) adds that the perspective of the researcher should be made clear to the readers of ethnographic reports. However, an *emic* orientation does not always guarantee that the ease of a study or that it will be without problems. To further clarify, the study by

Carolan (2003) is an excellent example of an emic study; she describes her background as a midwife. The study investigated the experience of older first time mothers from 35 week gestation. As described earlier Carolan (2003) acknowledged her feminist leanings as well as her pro-natalistic stance. Interestingly Carolan (2003) reports that in the initial stages of the study there were personal tensions with her role and identity. Carolan (2003) had concerns regarding the separation of her research role from her identity as a midwife and mother. She felt that these personal tensions had a significant impact on the data she was collecting.

A feminist approach to this current study was initially of interest to me because of my professional background. In my nursing, midwifery and pharmaceutical careers the majority of my colleagues have been female. In addition I have also lived and worked in Denmark which has a progressive approach to gender equality such as the state's attitude to childcare which is seen as the equal responsibility of both male and female parents.

I have theorised that the population of the sampled groups will be predominately female, there is also the expectation that males will also be present in the group meetings. Additionally it has been reported on page 37 that the experience of chronic pain equalisers across the genders around the age cohort to be recruited for this study. Although mixed gender field sites have been described as suitable for a feminist approach (Reinharz, 1992), of real interest to this current study is the feminist approach to ethics. Feminist researchers often use prescriptive ethics such as reciprocity, honesty, accountability, responsibility, equality in order that participants of ethnographic studies

are treated with respect (Skeggs, 2001). The implication of this ethical stance influenced the data analysis and is discussed in greater detail in chapter 5.

Conclusion

In this chapter I have described the methodological approaches that were available to me for the study of the sampled support groups. Ethnography is the chosen method because it offers researchers the ability to be immersed in their chosen research field and become part of that particular culture. Ethnography also allows for interactions within the social setting and assumes that personal engagement with the subject is important for understanding a particular culture or social setting. In addition a feminist ethical approach to ethnography helps to contribute to the respect of those in the studied setting by lessening the interpretative authority of the ethnographer which dominated this stance in European colonialism.

The minimal professional input that defines support groups has had an impact on my knowledge which has been limited to a basic understanding of their purpose. I am aware that they are venues for people with a common problem to come together and they offer social support. These aspects of support groups are discussed in the literature but the format of the information and methods of broadcasting are not discussed in detail. The routes that people take to joining a support group are also discussed but do not suggest that there may be multiple motivating factors or whether these factors change overtime. Another important factor is when in the illness experience support groups can be of most benefit. These gaps in the literature form the theoretical framework for this current study and are important in furthering our understanding of the benefits as well as negative aspects of groups. The purpose of this study is to contribute to the existing

knowledge as well as generate understanding of the purpose as well as when a group is beneficial to older adults.

Chapter 5 - Methods

An Ethnographic Study of Support Groups; the Pain Accounts of Older Members

5.1 Introduction

This chapter will describe and discuss the processes and approaches utilised in this current partial feminist ethnographic study. The justification of the methods I employed in the identification, location and short listing of the sampled groups will be discussed as well sampling decisions and data collection. My background and previous observations of support groups from both my nursing and pharmaceutical careers will also be reported. I will also present the observational checklist and discuss the interview schedule which was informed by sensitising concepts cleaned from the chronic pain and support group literature. The ethical considerations and management of the data will also be identified. Finally I will discuss how I sought trustworthiness and authenticity (Bryman, 2008) with the sampled groups as well as the interview participants.

5.2 Research Design

The planning of the current study was developed around the processes highlighted in figure 5.1, page 191. The final study was iterative, cyclical and interconnected which was the result of the initial plans being altered as the processes developed.

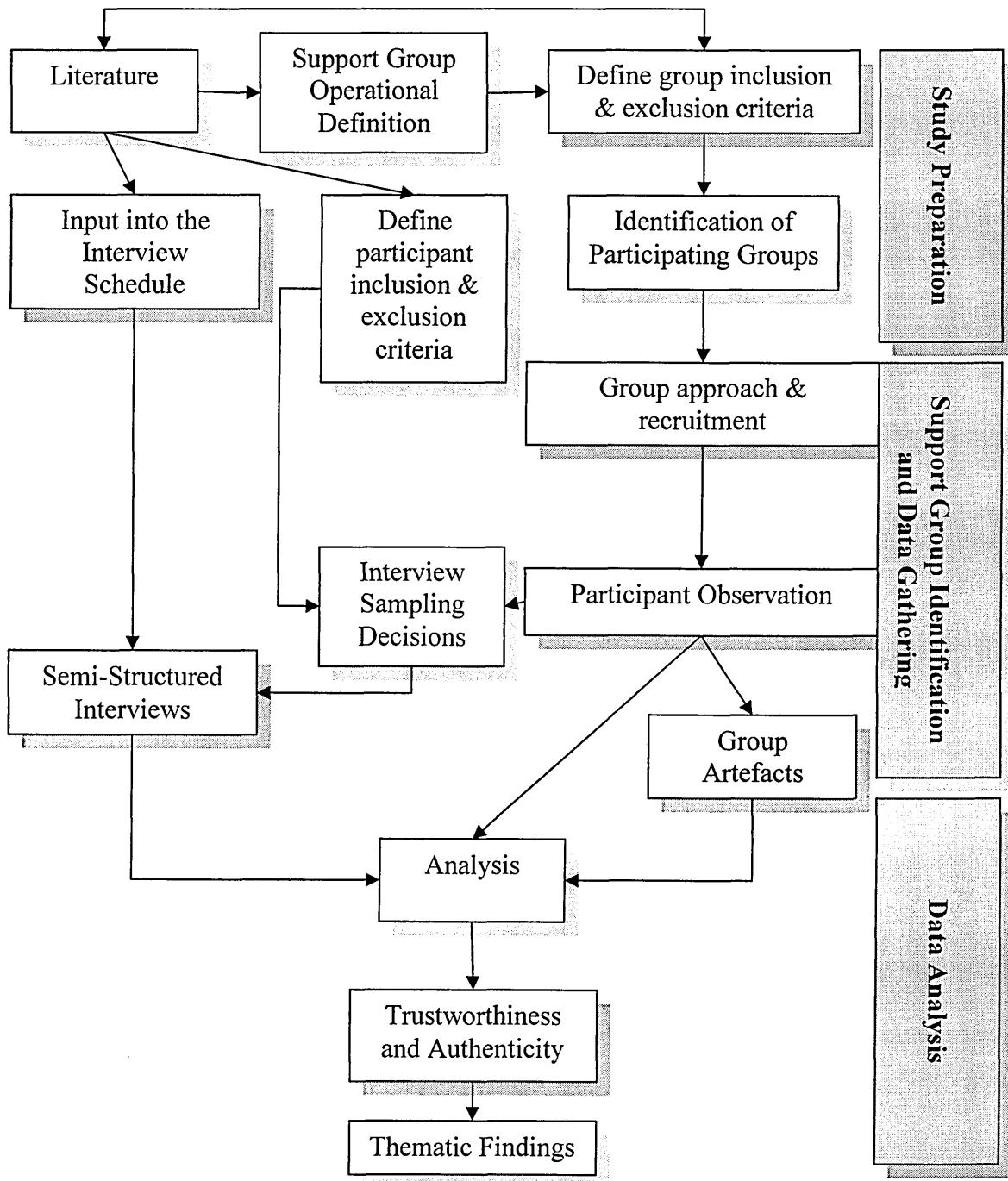


Figure 5.1: Overview of the development of the research design

5.3 Justification of Method

This section describes the reasons underlying the choice of methods for this current study. This includes group sampling, data collection, participant observation, use of field notes, the semi-structure interviews, trustworthiness, authenticity and generalisability. A description of the actual methods used is given in the rest of the chapter starting at 5.5.

5.3.1 Group Sampling

The reviewed support group literature was beneficial in identifying the operational definition (chapter four, page 171) of a support group and where they may advertise. The operational definition informed the inclusion and exclusion criteria for the support groups (table 5.1, page 205) to be sampled. This criterion was developed prior to locating the groups to ensure efficiency in identifying groups to be sampled. The search for the groups included online searches (Dibb and Yardley 2006), local search (Hatzidimitriadou, 2002), known contacts (Subramaniam et al, 1999; Butow et al, 2007), as well as primary and secondary health care locations (Hatzidimitriadou, 2002; Subramaniam et al, 1999; Butow et al, 2007) and snowballing (Butow et al, 2007).

5.3.2 Data Collection

The approach to data collection was formed around a *natural sequence* in order that data could be gathered logically and effectively. This approach began with the participant observation of at least two of the sampled groups meetings using an observational checklist (figure 5.3, page 214). Following the initial observations of the meetings the semi-structured interviews took place.

5.3.3 Participant Observations

Participant observation is described by Emerson et al (2001) as establishing a natural setting on a relatively long term basis in order to investigate, experience and represent the social life and social processes that occur in that setting. In the chronic pain support group study by Subramaniam et al (1999) the researcher attended five group meetings and six committee meetings over a 6 month period. The researcher participated in group activities as appropriate but was not a full member of the group and attended primarily as an observer. In contrast for this current study I intended to observe the sampled groups for 12 months. The primary reason for observing the sampled groups for this length of time was due to the unpredictability of chronic pain and its consequence to the semi-structured interviews of the older adult members. The decision also related to the impact that seasons and weather may have on group attendance. The age cohort of the population in the Subramaniam et al (1999) study was more general in contrast to this current study where the focus is on older adults.

In the Subramaniam et al (1999) study it is not stated what the researcher observed during the meetings of the group and the data from this does not appear integral to the study's results. This confirms in some way that the complex character of groups makes it difficult for researchers to understand and measure what is going on there (McDermott, 2005). In response I developed an observation checklist (figure 5.3, page 214). In this checklist I have identified four areas for observation including group members, environment, guest speakers and general group activities.

Due to the age cohort of the studied population I wanted to explore the groups approach to isolated members. In more general terms I observed the networking opportunities available at the meetings including the planning of coffee breaks which would allow group members to mix with others. I wanted to observe time off activities, these I identified as being socially important and included trips organised by the group as well as other activities that would not necessarily be support group related e.g. quizzes. Finally I wanted to observe the reaction of members to guest speakers such as the number of questions asked, the provision of further information such as handouts, the number of members making notes as well as verbal commentary of group members during coffee breaks. Aspects of the observational checklist impact on each other and could have an influence on success of the group. An example of this is how the room layout may impact on abilities to network.

The complete observer role was used in the study by Subramanian et al (1999) and was adopted in the initial stages of this study when locating the support groups. Unlike Subramanian et al (1999) this observational stance did not continue after the support groups were sampled. The decision to observe the groups as a participant was informed by the feminist stance of this current study e.g. non-authoritarian. This stance allows interpretative discussion and clarifications of actions/phenomenon amongst the researcher and the group members.

5.3.4 Field Notes

The use of field notes and memos in ethnography is elementally important. They are a form of representation and a way of reducing just observed events, persons and places to written accounts (Emerson et al, 2001).

Furthermore by reducing the confusion of the social world to written words, field notes constitute and reconstitute that world in preserved forms that can be reviewed, studied and thought about time and time again (Emerson et al, 2001). According to Emerson et al. (2001) field notes are not written in accord with some tightly pre-specified plan or for some specifically envisioned ultimate use. They are open ended, composed day by day with changing as well as new directions, field notes are an expression of the ethnographer's deepening local knowledge, emerging sensitivities and evolving substantive concerns and theoretical insights.

There is a consensus in the literature that field notes are written up as soon as possible after leaving the studied place or people (Emerson et al, 2001; Bryman, 2008). This aspect of ethnography is described by Emerson et al, (2001) as close to the field transformations of experiences and observations.

5.3.5 Semi-structured Interviews

The semi-structured interviews of older adult group members followed the observation of at least two group meetings. In order to answer the research questions (chapter 4, page 170) an interview schedule was developed (Appendix 3, page 409) from sensitising concepts gleaned from the chronic pain (chapter two) and support group literature (chapter three). Sensitising concepts are often used to generate theory in ethnography and proceeds to use participants' understanding of their experiences to develop and contest such concepts (Skeggs, 2001). The use of sensitising concepts contributed to the development of the interview schedule from two stances, the impact of chronic pain and membership of the support group. The questions were based around the support group and the impact of chronic pain.

The focus of the support group questions related to routes and decisions to join, the perceived benefits, the contribution the group may have had on the acquisition of new skills and management techniques. The impact of their chronic pain focused on the length of experience, when they joined the support group within this trajectory, the impact the chronic pain has had on their natural social network and the information provision within the formal healthcare system.

Sampling decision for the semi-structured interviews was informed by the qualitative research literature. According to Patton (1990) qualitative inquiry typically focuses in depth on relatively small samples, even single cases. The central importance of sampling is to select information rich cases, which are defined by Patton (1990), as individuals we can learn a great deal about the issues of central importance to the purpose of the research, thus the term purposeful sampling. The logic and power of sampling depends on selecting a truly random and statistically representative sample that will permit confident generalisation from the sample to a larger population (Patton, 1990). There are several different strategies for purposefully selecting information rich cases according to Patton (1990) of relevance to this study is opportunistic sampling. This approach to sampling is in response to the nature of fieldwork which often involves on-the-spot decisions about sampling that takes advantage of new opportunities during actual data collection. Patton (1990) suggests that being open to following wherever the data lead is a primary strength of qualitative strategies in research, this permits the sample to emerge during fieldwork. Patton (1990) also suggests that this method offers flexibility to the ethnographer

5.3.6 Trustworthiness

In the literature there is a suggestion that qualitative studies should be evaluated by using different criteria to that used for quantitative studies (Bryman 2008). Lincoln and Guba (1985) and Guba and Lincoln (1994, 2005) propose that it is necessary to specify terms and ways of assessing and establishing the quality of qualitative research as an alternative to reliability and validity. Their suggestion is two criteria for assessing a qualitative study; trustworthiness and authenticity (Bryman 2008). Guba and Lincoln (1994, 2005) describe the simple application of reliability and validity standards to qualitative research as unsuitable.

The problem is that the criterion of reliability and validity presupposes that there is an absolute truth about the social world and it is the role of the social scientist to reveal this truth. The argument is there can be more than one and possibly several accounts (Guba and Lincoln 1994, 2005). Trustworthiness is made up of four criteria, each having an equivalent criterion for quantitative research (Bryman 2008):

- Credibility – If there can be more than one and possibly several accounts then it is the feasibility or credibility of the account that the researcher arrives at that is going to determine its acceptability to others. In order to establish the credibility of findings entails ensuring that research is carried out in accordance with good practice (Bryman 2008). Additionally, the research should employ a *respondent validation* technique, which involves submitting their findings to members of the social world who were studied for confirmation that the investigator has understood that social world.

Another technique involves *triangulation* (Denzin 1970), which refers to an approach that uses multiple observers, theoretical perspectives, sources of data and methodologies.

- Transferability – qualitative findings tend to be orientated to the textual uniqueness and significance of the aspect of the social world being studied (Bryman 2008). In response qualitative researchers are encouraged to produce thick description (Geertz 1973a). Lincoln and Guba (1985) argue that thick description provides others with a database for making judgements about the possible transferability of the findings.
- Dependability – Lincoln and Guba (1985) argue that to establish merit of research in terms of this criterion of trustworthiness researchers should employ an *auditing* approach. This entails that complete records are kept of all phases of the research process including problem formulation, selection of research participants, fieldwork notes, interview transcripts, data analysis decisions in an accessible manner. This would then mean that others act as auditors throughout and at the end of the process.
- Confirmability – recognises that complete objectivity is impossible in social research; the researcher can be shown to have acted in good faith (Bryman 2008). In other words the researcher has not overtly allowed personal values or theoretical inclinations to sway the conduct and findings of the research (Lincoln and Guba 1985).

5.3.7 Authenticity

Lincoln and Guba (1985) also suggest that in addition to the trustworthiness criteria described earlier, they also discuss criteria for authenticity. The criteria are as follows:

- Fairness – Does the research fairly represent different viewpoints among members of the social setting?
- Ontological authenticity – Does the research help members to arrive at a better understanding of their social world?
- Educative authenticity – Does the research help members to appreciate better the perspective of other members of their social setting?
- Catalytic authenticity – Has the researcher acted as an impetus to engage in action to change their circumstances?
- Tactical authenticity – Has the research empowered members to take steps necessary for engaging in action?

In reporting the findings of an ethnographic study, Byrne (2001) suggests that there are certain rules that should influence reporting. Ethnographical findings should provide a clear description of the studied culture. Byrne (2001) also suggests that themes are used to present the findings just like in other qualitative research. The researcher should also report their background and how they participated in the culture. Byrne (2001) like many other authors of ethnography suggest that research findings should be confirmed by the cultural group that is being studied.

5.3.8 Generalisability

Quantitative research has a standard aim of generalisability and this is normally achieved through statistical sampling procedures. There are two functions to this sampling technique. Firstly it allows the investigator confidence in the representation of their sample. Secondly this representativeness allows for broader inferences. These sampling procedures are usually unavailable to qualitative researchers. In qualitative studies data are often derived from one or more *cases*, it is unlikely however that these cases have been selected on a random basis. Often a case would be selected because it simply offers access and this was particularly the case in my decision to use opportunistic sampling (page 216).

5.4 My Background and Observations

The background, values and interests of the researcher play a part in colouring an ethnographic study and should be made apparent. Primarily I am a human being and will be interacting, observing, discussing and interviewing with other human beings. Professionally I have rejected following a traditional career route gaining experience in wide ranging health related areas. I am a Registered General Nurse, qualified for over 20 years. For eleven years I worked within the National Health Service. My nursing speciality was intensive and special care of sick neonates with an interest in growth and development as well as pain. For the remaining six years I was a Clinical Research Associate in the Pharmaceutical Industry. The role involved the safe and ethical co-ordination of phase ii - iv clinical trials. The therapeutic areas included dementia of Alzheimer's type, Parkinson's disease, neuropathic pain, chronic unexplained pain, pre-menstrual syndrome and various mood disorders.

During my pharmaceutical and nursing career I was aware of support groups for various medical conditions. In my nursing career a support group for parents of babies who were admitted to a regional intensive and special care baby unit was established. The group was lay led as with minimal professional input from medical consultants, nursing staff and physiotherapists. A room at the hospital was reserved for the monthly meeting, parents were made aware of the group and the meeting times and the group leader (whose baby has been admitted to the neonatal intensive care unit and survived with complex needs) often visited the unit to talk to parents about the group and recruit new members. The babies remained in hospital for months at a time and the group was established to support the parents during this anxious time. The group also performed other functions like the set up of a clothes library where parents could ‘borrow clothes’ for a small deposit. This helped many parents who were often struggling financially and preterm baby clothes were often more expensive. The group also loaned breast pumps and supported parents who were expressing breast milk for their babies. There were occasions when the nursing staff needed to intervene in the group, particularly when it became evident that elements of tribalism became apparent. Tribalism in the context refers to the group becoming closed to new members because there was an established dynamic which many thought would diminish if new members attended the meetings.

The group leader was responsive to this and made members aware of the purpose of the group to support parents of the preterm or sick neonates. The group had roughly eight to ten members attending the meetings at any one time. The group leader was also encouraged to establish or make parents aware of other groups that were available such as BLISS or groups for cystic fibrosis as a way of developing a progression of support. Many of the babies were discharged from the unit with a number of long-term conditions and it was felt that parents’ needs differ after discharge.

Those who did not participate in the group cited having enough support at home as well as the perceived uniqueness of theirs and their baby's particular circumstances as a reason for not attending.

Additional awareness of support groups was made during my pharmaceutical career where the company offered donations to charitable organisations. These donations were often made in the form of sponsorship for annual conferences or information leaflets where the company's logo could be displayed and their corporate social responsibility could be fulfilled. Additionally knowledge regarding information about clinical trials was shared and often advice from the charitable organisation was sought, an example of this was the development of Patient Information Sheets for clinical trials. However two articles appeared in national newspapers which suggested that this alliance is not without commercial gain for the pharmaceutical industry. In an article in *The Independent on line* on the 1st October 2008 (Laurence 2008), it was suggested that the pharmaceutical industry *bankroll* national organisations in order to attack the National Institute of Clinical Excellence (NICE).

The extent of the drug companies' support for the smaller charities has led to criticisms that supposedly grassroots patient organisations are puppets of the pharmaceutical industry, being used to bludgeon NICE into making drugs available on the health service.

(Laurence, 2008)

These are similar to findings that were reported in *The Times on line* on the 23rd September 2006 (Crompton 2006), where an article asked of the relationship between national organisations and the pharmaceutical industry: who pays the piper?

In conclusion my previous group experience has influenced aspects of this current study. The special care baby unit group acted as a stepping stone to other support groups and as I reported in chapter three that previous group experience can be a motivating factor for joining other support groups.

I had less contact with support groups in the pharmaceutical industry as the marketing departments of the companies I worked for handled the strategy. Although there is criticism of the industries' influence with charitable organisations, my opinion is less clear cut. The charitable organisations often wanted well presented information booklets which were intended for health professionals as well as those experiencing the illness. There was also the expense of funding annual conferences which donors may find an unpalatable way of spending money. Additionally the role of NICE is never going to be viewed as popular as decisions that are made affect individuals directly. I am in conflict in that I am realistic about the need for NICE due to the spiralling costs of healthcare but I also believe that their decisions should not go unchallenged.

5.5 Methods

In the preceding section of this chapter I have explained the reasons underlying the choice of methods. The remainder of this chapter will describe what methods were actually carried out and how this was done. This section deals with locating and approaching the support groups and the interview participants. The ethical considerations of this current study including the regulatory requirements, the consent of the groups and individuals as well as the safety and wellbeing of the researcher will also be described. The observational checklist used in the participant observations of the sampled groups will be presented. The data collection and analysis will also be reported.

5.6 Location and Approach of Support Groups

In an ethnographic study the approach adopted by the investigator will help to gain and maintain access to the social setting being studied. The success of how the chosen methodology is accepted in the groups relies to some extent on how the ethnographer is seen by the members. This includes confidence and an ability to communicate with group members (Bryman, 2008).

The strategy employed to conduct the search was to divide the map of a city like a pie into six segments, and select one segment which included primary and a secondary healthcare location for the search. The selected segment had a variety of socially contrasting locations which included inner city (affluent as well as less affluent) urban (including social and private housing estates), semi-rural and rural.

5.6.1 Locating Support Groups

The support group inclusion and exclusion criteria is presented in table 5.1, in addition to the operational definition of the groups (chapter 4, page 171) they also needed to have a representation of the older adult cohort to be interviewed. The group inclusion and exclusion criterion was developed and implemented to ensure that the correct sample was identified. Following the development of the criterion the search strategy began. The inclusion and exclusion criteria of the interview participants is discussed later on page 216 and are presented in table 5.5 on page 216.

Support Group Sampling
Groups that were included
<ul style="list-style-type: none">• Chronic pain support groups• Chronic illness support group with chronic non-malignant pain as a symptom• Lay leader with some professional input (advice, presentations)• Regular face to face meetings (at least monthly)• Has a representation of older adults
Groups that were excluded
<ul style="list-style-type: none">• Cancer support groups• Support groups that are online only• Groups that are solely led by a professional• Groups that are curriculum based• Groups that have a defined membership length

Table 5.1: Support Group Sampling

Notes were made from the groups that displayed flyers or advertisements in each of the searched locations and included group purpose (e.g. arthritis support), frequency and times of the meetings, contact details including web addresses and telephone numbers.

5.6.2 Online Search

This search was conducted before any of the other approaches and was in response to Dibb and Yardley (2006) study which identified two data bases where information regarding 2000 support groups was available. The online search was performed using Google because of its popularity in the United Kingdom (UK). The initial search included the term '*support group data base*' and '*data base of support groups*' with the option of '*United Kingdom only*' pages being checked. This search was further refined after no significant results were returned. Filters were applied to the online search and included UK only web pages, excluding cancer and online groups. Keywords used for the search were '*chronic pain*' '*support group*' and '*self help group*'. The term '*Mutual aid*' was not used as a key word because unlike the United States of America (USA) it is not a naturally occurring phrase in the vernacular of people in the United Kingdom (UK). The internet search identified the local fibromyalgia group but the remaining results were online forums for chronic pain.

5.6.3 General Practitioner Surgeries

I visited a selection of GP surgeries in the segment of the city that became my search focus. This search involved the waiting areas without contact with surgery staff. The size and diversity of the population that the surgery served was not assessed, table 5.2 shows the results of this search.

Surgery Location	Support information available
Rural	Limited, no visible advertisements.
Semi-rural	Posters advertising local weight loss groups, smoking cessation, carer groups, cancer groups (prostate, breast and general). Mother and baby groups, local fibromyalgia group.
Urban (inner city)	Posters advertising NHS smoking cessation groups in multiple languages, local fibromyalgia group, mother and baby groups, English language courses and surgery clinics available such as immunisation clinics, diabetes, asthma and hypertension.
Suburban	Posters advertising local weight loss groups, smoking cessation, carer groups, cancer groups (prostate, breast and general). Mother and baby groups, local fibromyalgia group, drug and alcohol misuse groups.
Affluent urban (inner city)	Posters advertising Buddhist meditation groups, yoga, Pilates, carer groups, Alzheimer's, Parkinson's, tinnitus, cancer (prostate, breast and general), drug and alcohol misuse, local fibromyalgia group and mother and baby groups.

Table 5.2: Search Results General Practitioners

5.6.4 Secondary Care Out Patients Department

The rheumatology out patients department advertised the local fibromyalgia group. The department also held information booklets and help lines printed and supplied by Arthritis Care UK. Within this information was a website address to help individuals locate support groups in their locality.

5.6.5 Charitable Organisations with an Interest in Older Adults

Help the Aged were not aware of any chronic pain support groups in the locality. In contrast, Age Concern had completed two lists of national and local chronic illness support groups. The national list had been compiled in conjunction with the Scottish NHS. The list included web addresses of the groups and contact details. Additionally, Help the Aged and Age Concern suggested approaching local libraries as well as the local council.

5.6.6 Local and Central Library

This search proved to be unfruitful, although these locations had information relating to literacy and numeric support groups there were no health related groups. A member of the library personnel also suggested approaching the local council as they funded support groups and kept a comprehensive list. However, the list composed of support organisations for social not health related issues such as debt, violent partners and carer support organisations.

5.6.7 Known Contacts

In this study snowballing was employed when asking for known contacts of the supervisory team. These included contacts within the local National Health Service (NHS) pain clinics. The sources used in locating support groups are presented figure 5.2.

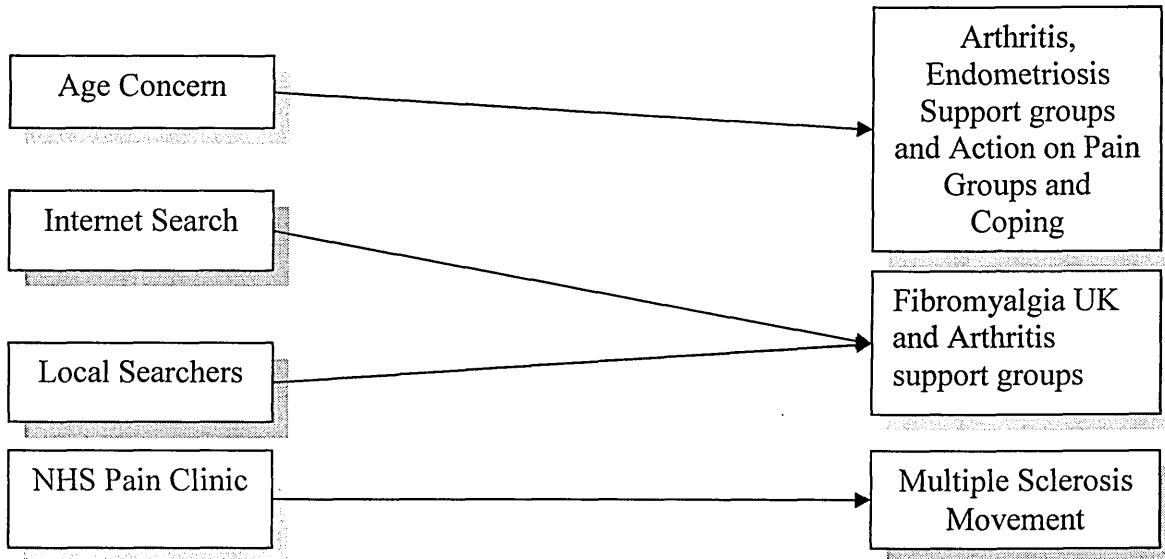


Figure 5.2 The Sources used in Locating the Included Support Groups.

Table 5.3 on page 209 are the groups that were identified and approached by explanatory letter (appendix 2, page 407).

Group	Website	Location	Contacted	Responded	Source
Arthritis Care	Yes	Local chapter	Yes	Yes	Age Concern (snowballing, Butow et al 2007)
Endometriosis	Yes	Local chapter	Yes	No	Age Concern (snowballing, Butow et al 2007)
Fibromyalgia	Yes	Local chapter	Yes	Yes	Internet Search (Dibb and Yardley 2006)
Action on Pain	Yes	Limited to 2 location in England	Yes	No	Age Concern (snowballing, Butow et al 2007)
Pain Association Scotland	Yes	Limited to 1 location	Yes	Yes	Age concern/known contacts (snowballing, Butow et al 2007)
Multiple Sclerosis Movement	No	Local chapter	Yes	Yes	NHS Pain Clinic Staff (snowballing, Butow et al 2007)
Coping	Yes	Limited to 1 location	Yes	Yes	Internet Search (Dibb and Yardley 2006)

Table 5.3: the short list of groups suitable for study

5.7 Ethics

Information rich data often tied to age, social circumstances etc., obtained in qualitative investigations challenges attempts to maintain privacy, confidentiality and anonymity. However it is the responsibility of the researcher to protect the anonymity of the participant and keep data confidential by restricting access and concealing identities, locations and places.

In this current study digital audio sound files and subsequent transcripts were issued with a unique number that was only traceable to the interview participant by the researcher. Direct quotes are not easily identifiable because of the removal of data such as names of places, groups and individuals etc.

5.7.1 Protection from Harm

A requirement of this current study was that provision was made for any participants who may become upset or distressed by talking about their pain and group experiences. This provision was discussed with the group leaders prior to any interviews taking place. I am an experienced nurse and qualified counsellor but due to the role in the process I made further arrangements. All three group leaders informed me that the group members had contact details for them. All three groups were affiliated to national charities that provided help lines. Furthermore I took contact details of organisations that offered help across the range of chronic illnesses to each interview. The delivery of the interview was designed to be open which allowed respondents to avoid topics if they did not want to discuss them. The interviewer attempted to be aware of the participant's level of comfort in addressing different topics, asking for permission to continue a line of questioning if it appeared that the participant became upset or distressed.

This study did not require ethical approval from the National Health Service (NHS) because it did not involve NHS staff or premises. Instead the University ethical approval was more appropriate. The study was fully approved by Sheffield Hallam University, Faculty of Health and Wellbeing Research Ethics Committee (FREC).

5.7.2 Safety and Well Being of the Researcher

Personal safety is an important factor when conducting community based research. The health and safety guidelines implemented by the faculty of Health and Wellbeing at the University were followed. A named administrator within the faculty was informed of the location and time of the interviews. Any contact numbers that I had were also given. On my return I informed the administrator.

5.7.3 Consent

Two approaches to capturing informed consent were used for this study, for the group it was felt that verbal information (a presentation) and verbal consent would be adequate. The interview participants including carers/partners would be required to give written consent. I was the only one who would obtain consent from the participants, in this way full informed consent would be given through the clarification of outstanding questions or concerns from the participant, their family or their friends.

Interview participants were given an information sheet prior to agreeing to take part in the study. This gave them the opportunity to read the study information and discuss it with those close to them as well as the ethnographer. Only when the individual had weighed the risks and benefits of participation and had an opportunity to ask any questions would the consent form be signed by the individual and countersigned by the ethnographer, both signatures would be dated and both parties receive a copy.

Following the presentation of the study, group members would be asked if they had any objections to my participation and observation. Members who were reluctant to raise objections in the group setting or who had any questions were encouraged to speak to

me at the end of the meeting or in coffee breaks. The presentation of the study was made over a number of meetings due to casual nature of meeting attendance.

All participants, interviewees and group members were reassured that their confidentiality would be maintained in accordance with the data protection act (1998 and amendment 2003). In the write up of the data and consequent feed back to the group people were given the right to have their input into the study removed.

5.7.4 Data Protection and Management

According to the 2003 amendment of the 1998 data protection act (Information Commissioner's Office (IFO), 2010) those handling personal data are legally obliged to adhere to eight key principles. The principles are presented in table 5.4.

Those who collect and hold personal information must fairly and lawfully process it
Data should be processed for limited and specifically stated purposes
The information collected should be used in a way that is adequate, relevant and not excessive
Information should be used accurately
Information should not be kept on file for longer than is necessary
Information should be processed in accordance with an individual's legal rights
Information should be stored securely
Information should never be transferred outside of the United Kingdom without adequate protection

Table 5.4 - The 2003 data protection acts eight key principals (Information Commissioner's Office (IFO), 2010)

The handling of the data for this current study was in accordance with the Data Protection Act (1998) and the amendment (2003). Therefore identifiable data that is

related to respondents such as addresses and the audio recording of the interview was kept on a single computer with only me having password access. There was no-file sharing capacity, a firewall was used to prevent unauthorised network access, and up to date anti-virus software was in operation. All back up files on disc and paper copies of transcripts were kept locked in a filing cabinet in a locked office with limited access. Addresses and the participants' correct names would not be used to label computer files. Also in accordance with the Data Protection Act (1998) and the amendment (2003), it is planned that the research files will be deleted by physically destroying discs when they are no longer required. No data with unique identifiers was transmitted over the internet.

5.8 Participant Observation

Observational notes were made of the environment, guest speakers, group members and other group activities with a focus on how these elements contributed to the motivation to join a group and evidence of the impact these elements have on the self management activities of members. Observational notes were taken during or soon after groups' meetings, these were transcribed and checked for accuracy with each of the groups. Where available there was also a collection of group artefacts such as written information, minutes from meetings and newsletters.

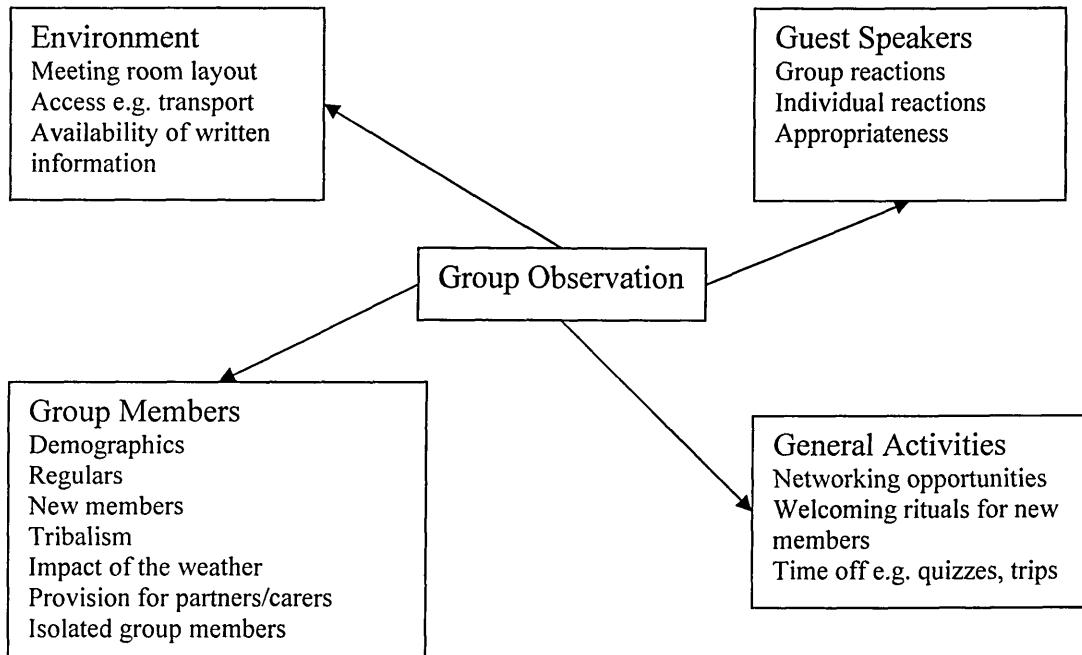


Figure 5.3 - The Observation Checklist

The environmental observations were made during the initial stages of group contact.

Notes were made of the location of the meeting room, accessibility including wheelchair access as well as links to public transport and car parking provision. The remainder of the participant observation looked at room layout, the provision of written information and the foot fall of people accessing and taking away the information. The observation of group members included identification of regular attendees and whether this led to tribalism e.g. regulars forming their own groups within the group.

Observation of elements of tribalism such as reactions to new members were in response to my previous experience of support groups for the parents/family of premature infants which I reported earlier as being problematic and potentially leading to the creation of a closed group.

The participant observation notes were made immediately after each of the group meetings, the exception was the Arthritis Group where notes were made on my return home due to the location and lateness of the meetings. The data obtained was coded with the headings from the checklist.

5.7.1 Field Notes

The field notes for this current study were often unruly and messy changing style as well as consistency or coherence, this loose quality of field notes is reported in the literature as a shifting quality of working which preliminary and transient rather than final or fixed (Emerson et al, 2001).

In this current study the format of the sampled groups resulted in differing approaches to note taking at the meetings. In the Fibromyalgia group note taking could be done overtly this was particularly the case when speakers were invited. Other group members were also taking notes and therefore I appeared to be behaving quite naturally. When there was not an opportunity to write notes of observations during the meeting, they were recorded as soon as possible after. In the MS group note taking was left until meeting close. This was because of the exercise component of the group. The Fibromyalgia and the MS groups met in the day and this was conducive for writing field notes as soon as possible. This was not the case for the Arthritis Care group. This group met an hour and half drive away from my home and the meeting finished at eight o'clock in the evening. Brief notes were made as soon as I returned to my car and field notes were written up when I returned home. The field notes made in or soon after meetings were written into transcriptions for analysis and coding.

5.8 Interview Sampling Decisions

The inclusion and exclusion criteria are listed in table 5.5, and was integral to the purposive sampling process. The use of self reported diagnosis was in response to participant's medical records not being accessed. I observed the sampled groups for at least two meetings before the semi-structured interviews began. When participants volunteered to be interviewed a contact telephone number was given and further study information sent to their home address. I would then contact them up to a week later to arrange an appointment.

Inclusion and Exclusion of Interview Participants

Interview participants will be included if:

- They are over 55 years of age
- If they have been diagnosed with chronic non-malignant pain for over 3 months (self reported diagnosis)
- They are currently experiencing chronic pain
- Able to read, write, hear and speak English
- Able to give informed consent

Interview Participants will be excluded if:

- They have chronic malignant pain
- They are unable to give full informed consent
- They are recently bereaved

Table 5.5: Inclusion and Exclusion of Interview Participants

The interviews were recorded and transcribed verbatim and checked for accuracy with the participants. The interview transcripts were then coded (page 222)

5.9 Data Collection

5.9.1 The Interview Schedule

The interview schedule (Appendix 3, page 409) was designed to indicate the topic areas, their sequence in the interview (Kvale 1996) rather than verbatim questions. This approach is described by Kvale (1996) as a criterion of *openness* by the interviewer. Choosing to interview in this way allows the participants to discuss aspects of the interview topics that were of importance to them (Kvale 1996). Additionally this would allow me to listen with what Kvale (1996) describes as an *evenly hovering attention*.

During the interviews I was sensitive to the needs of the individuals and offered frequent breaks for them to stretch, move positions or take refreshments. In addition I observed the person's pain experience such as non-verbal observations e.g. sitting position and facial expressions, as well as verbal statements. This was done in order to prevent the interviews harming the individual by exacerbating their chronic pain symptoms.

5.9.2 Post Interview Memos

Immediately following the interview notes were made about the process including impressions on how the interview was conducted, interesting statements or comments from the informant. Notes were made regarding discussions that followed turning off the recording device, although there are personal and ethical issues to their use. Notes were also made about the themes that had become apparent throughout the interview.

5.10 Trustworthiness

The method of ensuring credibility for the findings of this current study utilised elements of good practice such as informed consent, the development of the observational checklist as well as the development of an interview schedule. The decision to regularly discuss my interpretations and the emerging findings at meetings to the interview participant and the group as soon as possible had unforeseen advantages. These became apparent when two of the sampled groups closed which would have challenged obtaining credibility for the study from the group as a whole. Elements of the interview data which could have represented generalisability such as routes and reasons for joining were also discussed. In addition to seeking credibility from the perspective of multiple observers, the group members and the interview participants, the data was further triangulated with data obtained from the group artefacts such as the newsletter or minutes from meetings.

Transferability of the findings of this current study was tested during analysis of the observational notes as well as the interviews. In the analysis identification of issues that the sampled groups shared was of particular interest. Additionally recognising the uniqueness of each of the sampled groups was also reported. The long-term view of this current study was the possibility of conducting a larger study using the findings to develop a survey which would be issued to a larger cohort.

In this current study dependability was achieved by adopting the auditing approach suggested by Lincoln and Guba (1985). Records were kept of decisions made within the

phases of the research such as sampling decisions, field notes and post interviews memos. In addition comments made by the leader of the Fibromyalgia group of previous experience of researchers not feeding back data influenced my decision to continually update the sampled groups.

The feminist leanings that formed the basis of my approach to this current study helped in the confirmability of the findings. The issue of confirmability began during the presentation/discussion of the study given to the group at the beginning of my participant observation. Reassurances were given that anything discussed or noted of being interest would be anonymised for the eventual study outcome. Additionally to aid discussions with the group the participants would have access to notes and memos that I had made. Confirmability was identified as an issue which needed to be declared at the beginning of the process. Therefore in the introduction to the study I declared my professional background but emphasised that I was a former nurse. The primary issue was that my nursing background would influence the interpretations of the findings but through the use of explanations and discussions with participants of how I had reached conclusions would be open. I felt that it was also important that participants saw me as a researcher and understood that this was an evolutionary process for me.

5.11 Authenticity

5.11.1 Fairness

The issue of fairness was addressed by open access to the findings for the participants of the study and discussions and confirmation/rejection of my interpretation. Additionally

constantly updating the groups throughout the process helped to build strong researcher community relations.

5.11.2 Ontological Authenticity

This was particularly difficult because towards the end of the study because two of the sampled groups had disbanded. However I felt that it was still important that participants of these groups were given access to the study as this could inspire others to restart the group. This is in response to Skeggs (2001) comments that ethnographers with feminist leanings should always ask in whose interest the research serves. In the context of this current study, interest should lie in understanding the culture of the support group as well as sharing ideas with the groups and their charitable sponsors. This may be of use in further understanding of the role of these groups and who are motivated to join.

5.11.3 Educative Authenticity

This was achieved during the ongoing feedback and discussions of the study during the participant observation phase a number of emerging themes were discussed with members of the group. The group members felt that the point within their chronic pain experience that was likely to motivate them to become a member of a support group was very interesting and many reported that they had never thought about this prior to the study.

5.11.4 Catalytic Authenticity

This was achieved by reporting to the group the point in which members were likely to become part of the group and this was received with interest, particularly with the limited resources that groups tend to have. They felt that this finding could impact on

recruitment and in particular discussion with healthcare professionals about the group. It was felt that this new found knowledge would help target advertising resources with more efficiency.

5.12 Data Analysis

As I have reported in chapter four schema analysis (Ryan and Bernard, 2003) was employed in this current study. Schema analysis has similarities with grounded theory in that both begin with reading the verbatim texts carefully and seek to discover and link themes into theoretical models. Links between different segments or instances resulted in the fragments of data being brought together which created categories that had some common property or element. The creation of categories with and from the data helped me to condense the bulk into manageable units that were conducive to analysis. This *collapsing* of the data into thematic groups was an important element in reporting the findings and as such demonstrable evidence of this can be seen in a sample transcript (Appendix 4, page 410).

The transcripts from the observations, interviews and group artefacts were read through three times in their entirety. Marginal notes were made of emerging themes, as well as interesting quotes such as pain descriptors or novel self management techniques. The transcripts were also read by a member of the supervisory team and notes were made. This analytical process was conducted manually as it was important for me to keep *in touch* with the data, free hand memos were made which formed a conversation between me and the data, this technique helps in preventing writers block by creating fluidity in the data (Charmaz and Mitchell, 2001). The data was then coded.

5.13 Coding

Coding for this current study began with analysis because it raises analytical questions about the data. Coding was the first step in the development of theoretical categories. Through coding researchers start to define what their data are all about (Charmaz and Mitchell, 2001). When coding data the ethnographer takes an active stance with their data when using the schema analysis approach to coding. Therefore the ethnographer interacts with their data and not just the participants of the study. Secondly this approach allows the ethnographer to begin with open or initial coding and then try and code everything they see in the data (Charmaz and Mitchell, 2001). There were, however two different approaches to how the textual data was coded in this current study. The interview transcripts were coded line by line. Although it is reported by Charmaz and Mitchell (2001) that line by line coding poses an area of potential tension with ethnography. Any set of data has some level of interpretation written into it but line by line coding can be particularly useful with regards to interview transcripts. Line by line coding was employed so that I could stay close to the data. However the data also consisted of observed behaviour with little contextual framing, line by line coding was therefore not helpful. Charmaz and Mitchell (2001) suggest that coding whole anecdotes, scenarios and sketches may work better for the ethnographic observation aspect of this current study.

Memo making was also employed as it is described as a crucial step between coding and the first draft of a paper (Charmaz and Mitchell, 2001). Memos brought analytic focus to data collection as well as to my ideas. The use of memos also allowed me to play with these ideas, which entailed trying them out and checking their usefulness by

going back and forth between written pages and studied realities. The construction of memos is likened to free-writing or pre-writing by Charmaz and Mitchell (2001) and helped to reduce the risk of writer's block as well as increasing the fluidity and depth.

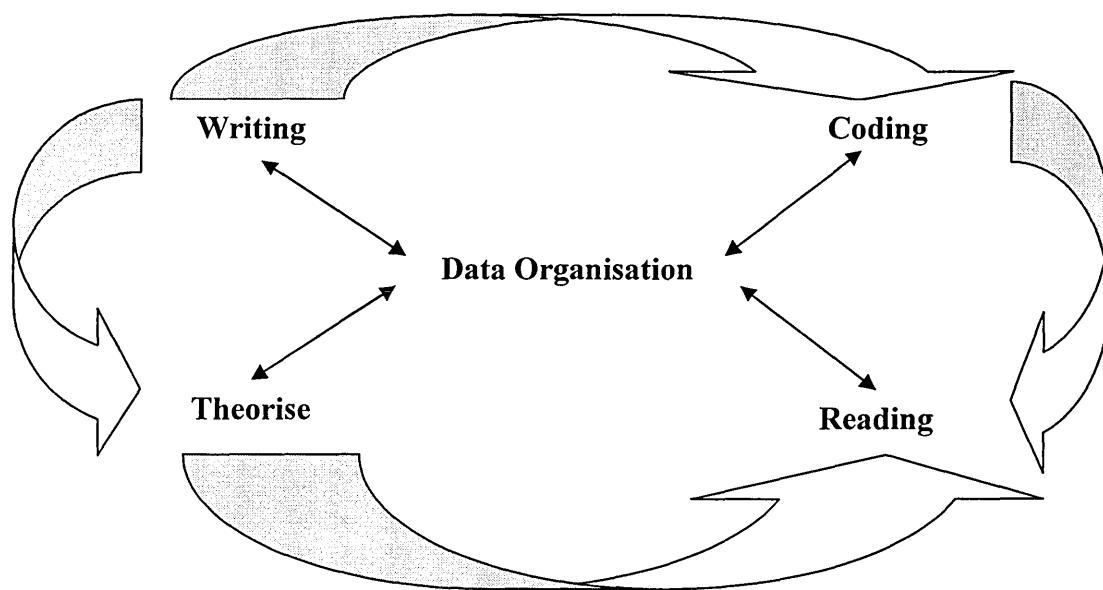


Figure 5.4: organising, coding, writing, theorising and reading (Tuckett 2005)

Chapter 6 – Study Findings

The findings of this current study are presented across three chapters. The first chapter will give an ethnographic perspective of the sampled groups. The source of the data from this chapter was predominately from the field and observational notes made during my participation in the sampled groups. Some of the data comes from the semi-structured interviews and was used to seek other interpretations as well as confirm and develop my own.

The second chapter will present the findings of the semi-structured interviews of the participants. The source data of these findings is from the verbatim transcribed interviews.

The final chapter will explore the social support activities of the sampled groups; these include *informational, emotional, appraisal* and *instrumental* support. These elements of social support have been recognised in the literature by Langford et al (1997). The source of the data for this chapter came from the participant interviews, field notes, memos and observations made during my participation in the group meetings. Additionally data from the groups' artefacts was also used as source data. The artefacts obtained for this current study include written information, handouts from guest speakers, verbal information from the group leader as well as guest speakers, minutes from meetings, group newsletters and magazine published by the charitable organisation. (The MS group however did not invite guest speakers due to the exercise focus of their meetings). The study findings are presented in an overall framework (figure 6.1 on page 225).

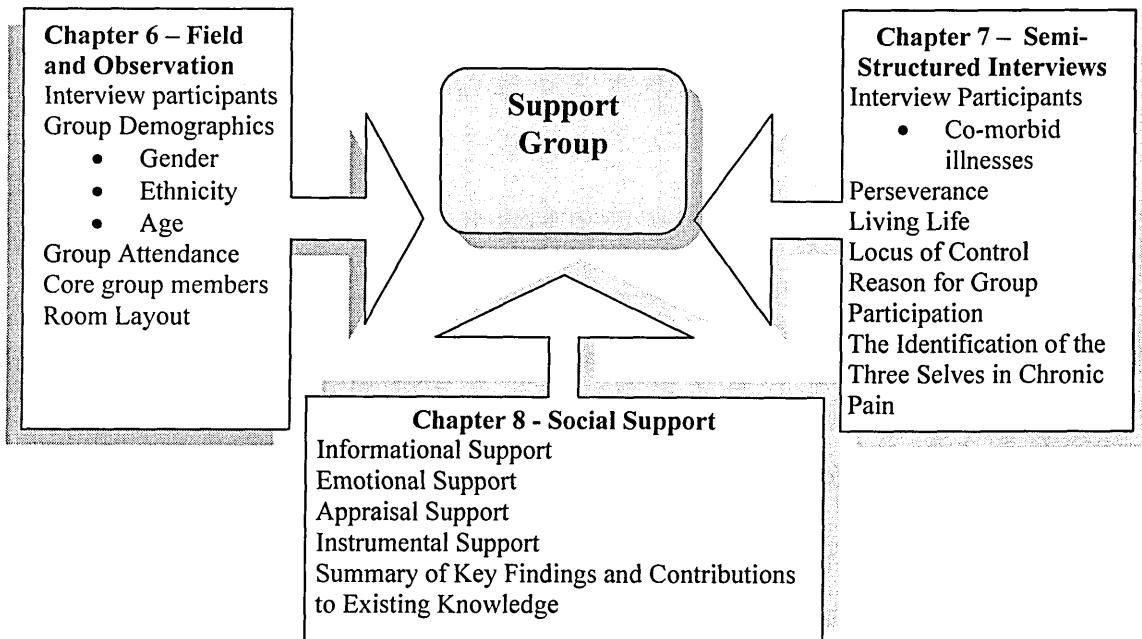


Figure 6.1. The chapters and themes in the overall framework

6.1 Study Findings: Field and Observations

The aim of this chapter is to present the ethnographic perspective of the three sampled groups included in this current study. This chapter will also introduce the interview participants identified through pseudonyms to protect their identity and respect their right to confidentiality and privacy.

The demographics of the group will also be reported in this chapter and this will include the gender, ethnicity, age and attendance of members. During the observation and participation in the sampled groups it was noted that a number of individuals attended meeting regularly. These members were also the source for the interview participants and were likely to have other roles within the group. These roles included committee members, fundraisers as well as organising and informal outreach programme. The

members who were included in this cohort have been named core group members in this current study.

The layout of the meeting room will also be presented and the impact this had on the observation and participation in the meetings will be discussed. In addition the layout of the meeting rooms may have potential negative and positive consequences for potential new members of the groups.

6.2 Interview Participants

As reported in the introduction to this chapter, data provided by the interview participants of the study will be used across all three of the findings chapters. Their contribution to the study was important because a number of the observations I made were discussed in the interviews. Therefore because of this contribution and for ease of reading I will introduce the pseudonyms and some brief biographical information (table 6.1, page 227). Chapter seven will explore the interviews further. Others within the group also made valuable contributions and were open to discussions during the participant observation of the sampled groups. I will refer to these individuals by their gender e.g. a female participant.

Table 6.1 shows the pseudonyms given to the interview participants as well as the background information such as primary diagnosis, secondary or co-morbid diagnoses are discussed in chapter 7, page 246, length of illness experience and membership length and previous occupation. The interview participants are discussed further in chapter Seven.

Pseudonyms	Primary Diagnosis	Length of Illness	Length of Membership	Previous Occupation
Brian	Rheumatoid Arthritis	25 years	5 years	Foundry Worker
Janet	Brian's wife interviewed together	N/A	5 years	Formal Carer
Deidre	Rheumatoid Arthritis	20 years	5 years	State Registered Nurse
Mary	Psoriatic Arthritis	5-6 years	5 years	Corporate Trainer
Alison	Trigeminal Neuralgia	15 years	6 years	School Lunchtime Supervisor
Hilary	Fibromyalgia	18 months	2 weeks	Registered Mental Nurse/ Mental Handicap Nurse
Jen	Fibromyalgia and amputation of toe	10 years	9 years	Civil Servant
Claire	Fibromyalgia	30 years	9 years	Fitness Instructor
Jess	Fibromyalgia	25 years	8 years	University Administrator
David	Fibromyalgia	25 years	3 years	Informational Technology - Banking

Table 6.1: The pseudonym of the interview participants

6.3 Group Demographics

The demographic information is presented in order to provide a *picture* of the participants involved in this current study. Future research may investigate why the sampled group did not reflect the diverse population of their locations. In the initial stages of my participation and observation of the sampled groups their demographics were recorded. This continued throughout the participation and observation period. This helped me to recognise that there was underrepresentation of diversity, as well as a core

group of members who attended the meetings regularly. Similar to the chronic pain support groups in the study by Subramaniam et al (1999), the Fibromyalgia and Arthritis groups encouraged members to bring their partners/friends/carers. The consequences of this are explored further in chapter 8.

6.3.1 Gender

The majority of the members of the Arthritis and Fibromyalgia groups were female. There was significant underrepresentation of males in the Arthritis group. The group leader and Brian the interview participant were male but for the majority of the observation periods I only saw two other males attend in a total of two meetings. In the Fibromyalgia group I only observed at total five males, two males were partners of people experiencing fibromyalgia. I also observed that the majority of the males in the Fibromyalgia and Arthritis group attended the meetings with another person, in this case either a partner or relative. One male attended his first Fibromyalgia group meeting alone but he never returned during my participation in the group. The male interview participants Brian (Arthritis group) and David (Fibromyalgia group) attended the group meetings with their partners.

The female to male population in the Arthritis and Fibromyalgia groups was similar to the high percentage of female representation (77%) in the group studied by Subramaniam et al (1999). What is not reported in the Subramaniam et al (1999) study is the gender of the people who were accompanied by their partner/carer/friend.

In contrast to the other sampled groups the MS group had equal representation of both males and females. I recorded in my observational notes that the exercise focus of this

group could be a factor. This is one of the findings reported in the Paulson (2005) study (chapter three, page 112), where there was also an equal distribution of males to females. The fitness instructor was male and the exercises often involved the use of kilo weights. I asked four of the male participants who attended the meetings regularly about their motivation to attend the group. Two males referred to the group meetings as '*going to the gym*' and it helped them feel good about themselves. They understood the importance of regular exercise and felt that they were contributing to managing their symptoms, such as stiffness. This view of the purpose of the group was also shared by the interview participant, Alison, who referred to the group as her '*keep fit class*'.

Initially the descriptors given by members of this group suggest that they were based in gender. However two other male participants viewed the group's purpose differently. A younger male saw the purpose of the group as providing a valuable resource for his sister who was also his carer. He explained that attending the group meetings allowed his sister to run errands such as shopping. The other male reported that he attended the group for company, and the exercises were secondary to the general group '*banter*'. In this context banter refers to the group conversations that were encouraged by the instructor and led by a dominant male group member.

The exercises performed at the group meetings were repetitive so that they could be remembered and repeated at home between the meetings. Those who found some of the exercises challenging, because of mobility issues, were offered aids such as broad latex bands that assisted with lower limb stretches or were offered alternative exercises. It was the instructor's intention that no-one felt excluded. I observed this during my participation in the group exercises, the instructor demonstrated the primary exercise

and then demonstrated an alternative which focused on the same area of the body. I often spoke to the instructor at the start of the meeting when I helped him to set up the room, he told me that he ran a number of similar exercise groups for the MS society across the region. He had not experienced MS himself and only charged his travel expenses to the charity. His income was subsidised by taking odd jobs such as a labourer, for a friend who was a builder.

6.3.2 Ethnicity

The ethnicity of the Arthritis and MS group was white. In contrast although the ethnicity of the Fibromyalgia group was in the majority white there were two females, who identified themselves as Somali and Afro-Caribbean. In addition the treasurer and secretary of the Fibromyalgia group was an Asian female who was on maternity leave during my participation in the group.

The lack of diversity of the groups was quite surprising given the diversities of the population in each of the locations where the groups met. Claire, the leader of the Fibromyalgia group was aware of the lack of diverse representation and was actively advertising in areas of high ethnic populations. Claire also reported in her interview that a number of ethnically diverse members used the group's telephone helpline.

'We do have er the ethnic minority join us you know and er so of them ring me monthly to tell me about what's happened with their job. And what they, if they are going through litigation and all that sort of thing.' (Claire)

Claire was unable to give a reason as to why these members chose to use the telephone helpline rather than attend the meetings. The reason may be as simple as their working hours. Claire believed that one of the salient issues for the low representation was

because of the language barrier. The core language of all of the sampled groups was English. The format of the groups, such as English speaking guest speakers, also meant that an understanding of written and spoken English was crucial to gain any benefits from attendance. Claire felt that advertising the groups in different languages would not offer a solution to this issue. In one of the sampled groups the lack of representation of other cultures became problematic when a racist comment was made by a member which went unchallenged.

6.3.3 Age

The age cohort of each group varied. The Arthritis group membership was predominately made up of individuals aged fifty years and older. The MS and Fibromyalgia group had a mixed aged cohort from twenty-five to eighty years old.

6.3.4 Group Attendance

The location of the meeting rooms for all the groups impacted on members attending the group. The Arthritis and Fibromyalgia group meetings were held in a room located in the centre of the town and city. The room used by the Arthritis group was next to the town's bus station and there was plenty of parking around the hall. As the hall was a recent and purposefully built venue there was easy access. The meeting hall for the Fibromyalgia group had easy access via public transport and had numerous car parking facilities within walking distance. However the cost of car parking may have been prohibitive to members on low incomes. The majority of the members I spoke to came to the group meeting via public transport and those with mobility badges tended to drive. In contrast the MS group's meeting was located some distance from the city centre and although it was served by public transport, bus and tram stops were located some distance from the hall. The meeting room was located in a redundant school which

had survived major redevelopment of the area. The houses that surrounded the school had been demolished some years earlier and replaced by light industrial units. What had not been refurbished were the roads and pavements surrounding the venue. The road was still cobbled and this made access to the venue by wheelchair a challenge. Members of the group who did use wheelchairs relied on community transport but this had to be booked weeks in advance. A female who relied on this transport explained to me that she felt anxious about using this resource as she hated to rely on others and felt it was further infringement of her independence. The remaining members' car pooled which involved picking up other group members within their home location. I spoke to the group leader about the venue and she explained that rents for the room in this facility helped to keep the cost of the weekly subscriptions payable by every member low and there were very few venues in the city centre that could cater for a group of people with issues of mobility.

The total membership of the Arthritis group was thirty four with between fourteen and twenty people attending the meetings. The lowest number of fourteen attendees was during the winter especially when the weather was bad. The group leader was aware of the issue of dark evenings being a barrier to some members attending regularly. To ensure a larger attendance at the group's annual general meeting a date was set in December, this was combined with the group's Christmas gathering and was attended by twenty-eight people. The group leader and others on the committee recognised the attendance in winter was an issue. Some members lived alone and did not feel safe leaving their homes in dark evenings. Members who were working also said that the dark evenings were potential barriers to them attending. One working female informed

the group that she felt less motivated in attending meetings in winter especially after working a full day.

The group attempted to resolve the issue of meeting times. Previously meetings had been held at six o'clock in the evening but there had been complaints from members who were working that this did not give them time to have something to eat or to unwind. At the group's annual general meeting during my participation, meeting times were again discussed. The leader told the group that they had been offered another time slot in the afternoon by the charitable committee that managed the venue and he wanted to know the feasibility of holding two meetings. There were mixed reviews to this with many of the older adults wanting the meeting times earlier. Those who worked expressed concerns that they would not be able to attend. Mary and Deidre, who were both interview participants, felt that splitting the group in this way would have negative consequences. The idea of another meeting was further quashed when the group leader announced that somebody else would have to lead one of the meetings as two meetings in one day would be too much for him. Nobody volunteered and as a result the group discussed other solutions including car pooling. Another idea that was explored was the community access bus. The bus was available for the times of the meetings and was subsidised by the local council and had access for those who used wheelchairs or had other mobility issues. An older female group member was clearly upset by this suggestion and did not want to use the access bus, she felt that because the bus displayed the easily recognised disabled symbol (a wheelchair user with a blue background) made people point and stare. She also felt that it would be a risk to her home security as people may be watching the house and were more likely to target her if they thought she was vulnerable. I spoke to her in the break and she told me that she

was paranoid about her home security as there had been a number of burglaries in the neighbourhood as well as nuisance caused by local young people.

The Fibromyalgia group had a total membership of sixty-four. The maximum number of members in attendance was forty but typically meetings were attended by twenty-eight to thirty members. When I asked group members about the venue they were very positive, the meeting room was located in the Quaker's Meeting House and was decorated brightly and simply as per the traditions of this particular religious group. Although the meeting room was located on the second floor there was access for members with mobility issues via a very small lift. Claire the group leader had taken time in finding a suitable venue, she told me in her interview that the room had to be bright with plenty of natural light due to the low mood symptoms of fibromyalgia that many of the members experienced. Previously the group had met at a Methodist chapel but Claire felt that the opaque windows and heavy dark oak furnishings were depressing and impacted on the benefit of group membership in a negative way. When I spoke to group members nobody voiced concerns about the times of the meetings and two members who were working managed to negotiate later starting times or days off for the meetings. They also felt that as opposed to weekly meeting, the monthly meetings helped in these negotiations and although they did not attend every meeting they managed to attend some.

The overall membership of the MS group was fourteen. There was only ever a maximum of ten members in attendance. A number of the members expressed their dislike of the venue and its location. Refurbishment of this venue was long overdue and the group met in the former school's vast gymnasium, the natural light came from high

windows but the state of the paint work did not make the venue light and airy. A male member of the group told me that the people who attended the meeting were more important than the venue. He was dominant in the meetings and commented on television programmes that he had watched in the week prior to the meeting.

He became the television *guru* of the group and many members had begun to watch the programmes he had commented about. I also watched programmes that he suggested to help me to participate in the group discussions. Humour was important and it contributed to feelings of togetherness that seemed to underpin this group's purpose.

A possible reason for the contrasting levels of membership across the sampled groups was advertising. The Fibromyalgia group were prolific advertisers and in the search I conducted in a segment of the city (chapter Five, page 204) they were represented in all of the medical practices as well as the out patients department.

The Arthritis group also advertised in similar health related locations across the town but they had special links with the local hospital. The group was originally started by a physiotherapist at the local hospital and she continued to have minimal input in the group. She had selected from her patients people who she thought would benefit from group membership, she even identified the current group leader and negotiated sponsorship from Arthritis Care. She continued to promote recruitment of this group by creating awareness and suggesting membership to patients she saw at the hospital. She also negotiated advertising space for the group at the hospital.

In contrast to the other sampled groups the MS group only advertised in the MS society's monthly magazine. The group did advertise widely in various locations but

recently the leader's health had resulted in her wanting to step down once a new leader was in place.

I noted the number of new members attending the meetings as a measure of the success of the groups' campaigns and the results were contrasting. The Fibromyalgia group attracted two or three new members consistently at each meeting and although some of these members only attended one meeting according to Claire (group leader) they remained members. Jen was one of the committee members of the Fibromyalgia group as well as an interview participant and I asked her about the non-returners. She informed me that this had been the pattern since the group had been formed. She believes that because of the nature of fibromyalgia, categorised as a medically unexplained illness, people who were newly diagnosed wanted to see others in similar circumstances and for many once they had done this they did not feel the need to attend the meetings again. Jen also believed that the membership of the group was a credit and debit system and the results were that '*it all balances itself out.*' She also suggested that many people came back to the group once they had accepted that there was no cure but this could be years later. Newly diagnosed members seeing others in similar circumstances and the comment by Jen is a key finding to this study. This helped towards the recognition of the three selves of chronic pain which is discussed in more detail in chapter seven page 269.

The Arthritis group only recruited one new member during my participant observation. The leader and other members did not seem unduly concerned about this and I noted that perhaps there were elements of tribalism within this group. The new member commented to me after she had attended three meetings, that the group should be

recruiting younger people to help to take it in new directions such as more socially focused and meeting in different venues such as public houses.

6.4 Core Group Members

One of the findings of the participant observation of this current study was the identification of a core group within all of the sampled groups. A core group member is an individual who attends all or the majority of group meetings. Some of these individuals were members of the groups' committee in the Arthritis and Fibromyalgia groups and the interview participants were all members of the core group. Although the MS group did not have a committee the core members were instrumental in developing an unofficial *outreach programme* which was also reported as one of the activities of the group in Subramaniam et al's (1999) study. The outreach programme was developed by Alison (interview participant) and two male core members and will be discussed in chapter eight, page 327. The core membership was vital for the survival of the group because of the sustained membership. In the literature there was nothing reported about core membership or regular attendees although Wituk et al (2002) makes reference to regular attendance at meetings giving individuals a sense of strong shared intimacy that may help prevent the group from disbanding.

6.5 Meeting Room Layout

The layout of the meeting rooms is not reported in depth in the support group literature. The observations of the sampled groups in this current study suggest that layout may impact on whether the group appears open or closed.

The group with the smallest core group membership was the MS group. The room used for the group meetings needed to be prepared prior to the arrival of the members.

During my participation of this group I helped the fitness instructor to move the chairs and prepare the room. A number of the members of this group used wheelchairs and chairs were placed so they could be easily moved to accommodate group members anywhere within the semi-circle of chairs. The chairs were used as a template for the overall room layout. In the group meetings I attended I chose to sit in different areas of the semi-circle. Field notes that I made about the layout reported that it was conducive for group members to do this. This, I reflected, gave the group an openness and this was further confirmed when a student who was on work experience from school asked to join the group at one of the meetings. After the meeting he told the instructor that he felt that the group members were welcoming and as a consequence he felt that this group was fun.

The Fibromyalgia group was similar to the MS group in that there was a small core group membership. The setup of the room was also needed prior to the meeting and I helped the partners of the leader and treasurer to do this. The chairs were arranged in a semi circle and two tables were placed in a ‘T’. The top strike of the ‘T’ was used by the leader and guest speakers during the meeting. The down strike of the ‘T’ was used to display the written information and the books from the group’s library. Although the room layout suggested a classroom it reflected the meeting style of this group. The group leader made announcements at the beginning of the meeting and then a guest speaker would talk for the remainder. The group members were less likely to gravitate to their usual chairs and I also was able to sit in different locations at each of the meetings. This gave a positive contribution to the participant observation aspect of this current study. The layout helped the group to achieve an openness, which two of the newer members commented on. One of the new members was a younger female who

informed me that the group appeared welcoming. She had made a couple of comments during the meeting and had even volunteered for a *hands on* demonstration with the guest speaker, a holistic masseuse. The group member said she was usually more reserved but the group had given her a feeling of being amongst friends.

In contrast the layout of the room used by the Arthritis group contributed to a more closed atmosphere. The room consisted of small tables each seating four people with trestle tables down each side of the room which were used by the group for written information as well as photographs and other artefacts from social events. I asked the group leader about the room layout and he informed me that the venue was used as a luncheon club during the day and that the management committee did not like the room layout altered. This resulted in the development of a larger core group who gravitated to the same seats at each meeting. I sat in the periphery of the group during my first couple of meetings. Mary was the only interview participant to comment on the room layout and offered me a further insight into why members may gravitate. The group has beverages and biscuits prior to the start of the meeting, this was repeated approximately half way through the meeting. Mary has observed that people with rheumatoid arthritis tend to sit together. This she believes is because of the affect that this disease has on peripheries such as fingers which can make eating and drinking challenging as well as causing anxiety because of the potential awkwardness in holding mugs as well as cutlery. Mary suggests that when they sit with others in similar circumstances they tended to converse more. Mary has also observed those who have had joint replacement surgery tend to sit together. She recognises that because she has psoriatic arthritis and as the only one in the group to experience this, allows her to mix with both of these groups.

When I returned to this group to discuss the findings of the study, the members did not recognise that this was occurring. However one member felt that because of the different types of arthritis it was only natural for the individuals to gravitate to each other, these micro groups she suggested, acted as a support group. Grande et al (2006) suggested that clinical characteristics of illness were not an important determinate to joining a support group (chapter 3, page 132). What the observations of the Arthritis group in this current study suggest is that clinical characteristics may be important in the decision to continue attending group meetings. Another consequence of the room layout for this group was when the group leader made announcements concerning a group members who were absent due to their health he referred to where they sat at the meetings as a way of helping to identify the person.

Summary of Field Notes and Observations

In this chapter I have reported aspects of the ethnographic perspectives gleaned from a variety of source data such as interview transcripts, comments made my group members and leaders and from memos and observations I made during my participation in the group meetings. Generally each of the groups differed in their content and this has been reported by McDermott, 2005) but their similarities as well. These included the recognition of the core group.

Females were unsurprisingly the largest represented gender but only in the Arthritis and Fibromyalgia groups. In the MS group there was equal representation of both genders and this was reported in a similar exercise group in the study by Paulson (2005). The reason for the gender distribution in the Arthritis and Fibromyalgia groups has been identified in the chronic pain literature (chapter 2). The epidemiological study

conducted by Macfarlane (2001) and later by Breivik et al (2006) reported that a higher proportion of females experienced chronic pain. Secondly from a sociological aspect the approach by women to health related issues is more active than that of males (Morrison and Bennett 2006). Thirdly Wijnhoven et al (2006) also reported that gender socialisation has resulted in females being more willing to be self disclosing. The results of this are that females have an increase in their verbal skills and symptom awareness which has the predisposition to take action in response to symptoms.

The support group literature that was reviewed in chapter three did not report on the ethnicity of the studied groups. I was very surprised that there was an underrepresentation of a more diverse population in the two locations of the sampled groups. The population of the groups did not reflect the population of the areas they were part of. Although Claire's continued attempt to reach out to others in the population was admirable she recognised that success was limited because of the language barrier.

The age of those that participated in the support group meetings was also comparable to those reported in the support group literature in chapter 3. However there was a division between the groups, the Fibromyalgia and MS group had the widest diversity of age. In contrast the Arthritis group had underrepresentation of the younger age cohort and this theme ran throughout the observation of this group. It was recognised by the charitable sponsor and the new member as being potentially problematic to continued interest in the group. The group did not appear to be unduly perturbed by the lack of younger adults.

Attendance at the groups was consistent but the weather and season impacted on people attending meetings at the Arthritis group. The recognition of the core group was not reported in the reviewed support group literature. The formation of the core could be salient to the continued success of the group. However groups need to be made aware of the dangers to group survival if tribalism becomes apparent.

One of the most interesting findings related to the room layout was the apparent grouping of arthritis within the group. The nature of this illness helps make sense of why this may happen but it provided evidence of support groups within support groups. I appreciated why this was happening particularly if people are conscious of the outwardly visible symptoms of their arthritis. However this had the potential of closing certain aspects of this group.

Chapter 7 – Study Findings: Semi-Structured Interviews

The aim of this chapter is to explore the themes that emerged from the interview accounts of the older adult members group members to answer the main and subsidiary research questions (chapter four, page 166).

Themes that have emerged include; *the differing perceptions of having a primary and secondary chronic illness* and *how this impacts on self management as well as medical consultations*. There was also evidence to suggest that the interview participants had psychological approaches to their chronic pain circumstances such as; *perseverance, self efficacy and locus of control*. Although these psychological aspects of the chronic pain experience were not measured formally the evidence of their existence will be discussed.

In the interview schedule (appendix 3, page 409) the participants were asked about what motivated them to join a support group. Their responses included; *a perceived informational deficit, a desire to increase their social network, starting the group and medical professionals' recommendations*. These motivational factors have been reported in the reviewed literature discussed in chapter three. What has not been reported in the reviewed literature but was found in this current study is *philanthropy* as a motivational factor which has an impact on active retirement and quality of life through the redefining of a social role. Additionally in the interview schedule (appendix 3, page 409) individuals were asked to give accounts of their chronic pain, including the history and when they sought support of the groups of which they are currently members of.

The analysis of the data from these accounts has helped to identify three selves within chronic pain trajectory including *the past*, *chronic pain* and *present self*. The identification of these three selves contributes to the body of knowledge because individuals experiencing chronic pain, health professionals, patients' associations' group organisers and charities sponsoring groups can locate when support group membership can have more of an impact within the chronic pain trajectory.

7.1 The Interview Participants

Table 7.1 on page 245 presents the biographical information of the interview participants, to keep the identity of the individual confidential and maintain their privacy pseudonyms have been given.

Pseudonyms	Primary Diagnosis	Length of Illness	Length of Membership	Previous Occupation
Brian	Rheumatoid Arthritis	25 years	5 years	Foundry Worker
Janet	Brian's wife interviewed together	N/A	5 years	Formal Carer
Deidre	Rheumatoid Arthritis	20 years	5 years	State Registered Nurse
Mary	Psoriatic Arthritis	5-6 years	5 years	Corporate Trainer
Alison	Trigeminal Neuralgia	15 years	6 years	School Lunchtime Supervisor
Hilary	Fibromyalgia	18 months	2 weeks	Registered Mental Nurse/ Mental Handicap Nurse
Jen	Fibromyalgia and amputation of toe	10 years	9 years	Civil Servant
Claire	Fibromyalgia	30 years	9 years	Fitness Instructor
Jess	Fibromyalgia	25 years	8 years	University Administrator
David	Fibromyalgia	25 years	3 years	Informational Technology - Banking

Table 7.1 The interview participants

The interview participants were from a variety of occupational backgrounds. The primary illness was identified as the one for which participants sought support group membership for. The majority of the participants were also experiencing comorbid or secondary illnesses and the impact this had on self management as well as medical consultations will be discussed later in this chapter. The interview participants had been experiencing their chronic illness for between five and twenty five years with the exception of Hilary who was only diagnosed eighteen months prior to group membership.

This impacted on how Hilary saw the effectiveness of the group within her particular trajectory and has helped to identify the three selves within chronic pain which is discussed in more detail on page 269. The interview participants for this current study were either white British or white Irish.

7.1.1 Comorbid Chronic Illnesses

In addition to the primary chronic illness Deidre, Alison, Jen, Claire, Jess and David reported that they had been diagnosed with a secondary or comorbid illness. Brian had experienced poly surgeries but primarily was still experiencing chronic pain from his arthritis.

The majority of those with comorbid illnesses were members of the Fibromyalgia group. Jen, Claire, and David were diagnosed with cervical spondylosis. In addition to this Jen reported experiencing phantom pain following the amputation of a toe she had five years previous. Jess experienced the occasional infestation of candida which was present internally in her gastrointestinal tract and externally on the skin of her trunk.

Although they identified that the comorbid illnesses were bothersome it was apparent that there was a gap between these illnesses and *the self*. To further clarify the interview participants did not identify themselves as cervical spondylosis, candida or amputee patients but saw themselves as *individuals* with cervical spondylosis, candida and an amputation. This is in contrast to their diagnosis of fibromyalgia where the symptoms were very much seen as part of *the self*.

Additionally those with cervical spondylosis demonstrated that they were capable of managing the symptoms well, an example of this was given by both Jen and David who used a combination of hard and soft cervical collars dependent on their activities or level of pain. Jen also noticed that if she used her hard collar too much it rubbed a trigger point at the base of her skull and as a result she avoided using this device as much as possible. Similarly Jess modified her diet, avoiding yeast, and consumed pharmaceutical products to manage her candida. Hilary did not spontaneously report any co-morbid diagnosis except asthma which she had been managing since she was a child.

Interview participants from the Arthritis and Multiple Sclerosis groups who reported co-morbid illnesses included Deidre, who was diagnosed with Crohn's disease and Alison who had multiple sclerosis. Although Alison attended a group for people with multiple sclerosis, she identified this as secondary to her trigeminal neuralgia. However, Alison successfully managed her trigeminal neuralgia through the identification of warning symptoms which indicated a flare up.

You get, erm, whistling in, whistling in your ear. (Alison)

Deidre remarked that having a diagnosis of Crohn's disease often challenged the pharmaceutical products she could consume for her arthritis pain. She has also required emergency surgery for a ruptured bowel which she suggested was the result of the older generation of arthritis medication. Deidre manages her Crohn's disease through diet. Neither Deidre nor Alison suggested that their comorbid illnesses made them *patients* but rather people who were experiencing them.

In addition both Deidre and Alison had experienced the loss of their partners around the same timescale. Unlike Alison, Deidre was able to come to terms with her loss. The data from Alison's interview suggests that she is finding it difficult to *move on* and this loss is more distressing than either the multiple sclerosis or trigeminal neuralgia. She was diagnosed with both these at the same time as her partner had died. During her interview the conversation reverted back to her loss and her grief as though this was a relatively new experience for her.

This aspect of how these individuals identified *the self* is important in contributing to our understanding of how those with chronic illness and chronic pain self-manage.

There is also evidence that those with a secondary diagnosis of cervical spondylosis saw it as the primary focus of health professionals during consultations. This led to them believing that cervical spondylosis *got in the way* of fibromyalgia for which they reported as needing more support. David's interview account helped to explain that the medically unexplained nature of fibromyalgia and the broad spectrum of symptoms experienced make communication of issues effectively to health professionals problematic. The focus on cervical spondylosis in medical consultations is further illustrated by a quote from David.

I went again today [to the GP] and examined me and they says you've got your spondylosis playing up. I've got pains from the top of my head to my toes (David)

David is managed medically by his GP surgery. In the past he remembers a consultation with a locum doctor which focused on his fibromyalgia and he felt elated.

'He was a smashing chap and he said "I do understand" and I came out and I got a lift and I thought oh thank God at last someone down there's gonna learn and listen. And then I finds out he is only temporary, God (laughs).' (David)

He found it difficult to communicate effectively with medical professionals (Sofaer-Bennett et al, 2007) because his faith in their ability to understand his health circumstances has been shaken. The origins of this are in the belief that he not listened too when he discussed his fibromyalgia, the focus is always the spondylosis.

'He's supposed to be the rheumatologist down there so I thought he should know about these things, so I went two or three times (secondary care, outpatient). He just, I don't know, he's mentioned fibromyalgia, just I don't think he's listening, he's not listening, he never makes notes about the fibromyalgia, he just keeps talking about spondylosis all the time, what I have had for a long time. He goes back to that all the time.' (David)

In the quote David identifies that he has experienced spondylosis for a long time and he informs me that he is managing the symptoms this secondary diagnosis well.

7.2 Psychological Approaches to Chronic Pain

The analysis of the data from the interview participants' interview accounts revealed elements of psychological approaches to coping and managing their chronic pain symptoms. These approaches were coded as *perseverance, self efficacy* and *locus of control* and are subheadings discussed below in the respective subheadings. The presence of these psychological approaches to their chronic pain circumstances have helped in the identification and development of the three selves of chronic pain (page 269).

7.2.1 Perseverance

In Sofaer-Bennett et al's (2007) study there emerged four distinct themes of what the older adult participants acknowledged as ideals in chronic pain self management. These include the desire for independence, adapting to a life with chronic pain, perseverance and successful communications with healthcare professionals.

Sofaer-Bennett et al (2007) acknowledged that of the four themes identified perseverance was the most dominant and was further divided into two distinct subthemes, keeping occupied and social activities. The data from the participants' accounts in this current study acknowledges that successful self management is dependent on perseverance.

'I've pushed myself all my life, that's why I am still here, that's why I started the group.' (Claire)

The accounts from Brian, Janet, Mary, Jess, Jen, Deidre David, Claire and Alison indicate the presence of these two distinct subthemes. Brian and Janet started new hobbies including swimming, a computer course and an over sixties gymnasium. Mary joined a tai chi group to help her achieve a good night's sleep as well as adopt a general feeling of wellbeing. Jess continued to attend church and various groups affiliated to the church. The remaining participants either continued with their existing hobbies or adapted their approach to be able to continue. David reported that he adopted pacing techniques in order that he could continue with his hobby of gardening. Claire started a Pilates group for members of the Fibromyalgia group and also experimented with a laughter workshop, the theory being that serotonin would be released as a natural analgesic. Jen continued to be a member of a scrabble group but took frequent breaks to prevent her trigger points from flaring up. Alison continued attending groups affiliated to her local church and used a mobility scooter to continue as she could not drive.

The Arthritis group was a further source for keeping individuals occupied through volunteering their time in street and supermarket charity collections. Interestingly during the participation and observation a focus group was organised by the regional office of the charity to discuss active retirement.

In the meeting following this focus group the group leader expressed disappointment that nobody had mentioned the Challenging Arthritis course for which the group had successfully obtained a lottery grant to send members on. The leader also mentioned other activities he had organised to help with an active retirement which included membership of the group's committee as well as street and supermarket collections. Group philanthropy was evident amongst the members of the Arthritis group and two of the interview participants identified this as an important factor for joining a support group (page 266).

The sampled groups in this current study had elements of other forms of socialisation which were divided into formal and informal activities. In the Arthritis and Fibromyalgia groups occasional days out were organised, the funding for these was provided for at the local level to prevent social exclusion. The sampled groups also organised Christmas gatherings, in the Arthritis and Fibromyalgia groups' members provided the catering. In the MS group the Christmas gathering was held at a venue where a sit down meal was provided and this was paid for by individuals in small instalments over the year. The core members of the MS group also organised an informal outreach programme which contacted and visited members who had become isolated because of an exacerbation of their symptoms which resulted in increased immobility.

7.2.2 'Living Life'

The interview participants in this current study demonstrated a readiness to change or adapt to help them to manage their chronic pain.

More importantly analysis of their interviews suggested that taking personal control of their circumstances helped them to achieve an improved quality of life.

Jess enjoys holidaying abroad several times a year however the chronic pain began to impact on her mobility. She reports that she no longer had the choices that *normal* people had regarding location. Further analysis of her account suggests that Jess meant that holidays were less spontaneous because they required extra planning in view of health circumstances.

'It's just it's just that when you go away you can't do it like a normal person. Can you? You can't just book a thing and think oh I will go there because like come places for instance I can, my daughter went to Spain this year she said "you couldn't go there mum because the hill was too much to the beach. I mean we have spent hours on the internet looking at hotels and you know just so I could you know go' (Jess)

Jess' greatest concern is that her chronic pain and increasing immobility impacts on her partner's holiday plans and as a consequence his retirement. He had retired three years earlier and to mark the event he paid for the family to visit a theme park in the United States of American (USA). The family included Jess and her grown up children and her grandchildren.

'Well it got near to booking it and I couldn't, I thought no way am I going.'

Jess reports that the thought of '*Holding everyone back*' began to cause her anxiety and as a solution turned to the internet to enquire about hiring a mobility scooter for the two week break.

'I went on the internet and I found a mobility scooter place (short pause) and I booked one but just for the, the fortnight you see and then we went again last year, well I knew again straightaway. I just e-mailed the hire place you see and I er had the scooter again.'

As a consequence of this Jess continues to enjoy the breaks away with the family.

Although she admits it took some getting used to, the result was that she '*could do what they could do. Well more or less.*' Jess has now purchased one for use at home and lighter version for holidays such as cruise she had booked for later in the year '*I mean all I have to do is fill a form in to tell 'em about it [the mobility scooter being brought on board]*'. Jess uses the scooter to help her when she is out shopping and reports that she is now able to do this independently. The use of the mobility scooter has contributed to her quality of life.

David reported to his general practitioner that sleep was the biggest issue he faced and the results of a consultation he had on the day of the interview is reported in chapter eight page 324.

'I can't lay in bed at night me spine hurts when I lay down, it gives me pins and needles and my hands are useless at night.' (David)

His inability to have a good night sleep has resulted in several adaptations being made by his partner. This included the purchase of an orthopaedic bed which seemed to help for a couple of months.

'I started getting worse with it, I got er a foam mattress, what's like all all eggs, egg shell, egg box shaped thing ,it so you can compress it with your[body]. So we got that and that helped a bit, just lately there's being nothing that will touch it what so ever, pain killers, I've had all the gels [analgesic gels] there is, I bought some myself. I've had TENS machine down there (pointing to its location), that doesn't touch it.'

David reports that his and his partner's adaptations only seem to work short term but he continues to try and pursue a realistic solution. Including purchasing a duvet which he doubles up and this has helped to support him, he does suggest that this will only be a temporary solution as there is a realisation that a pattern is emerging with his pain. That

is that solutions he finds are only temporary and '*you have to keep ahead of the game with this pain.*'

A number of the participants from the Fibromyalgia group were prepared to use *experimental* approaches to their management. These included following a dietary regime and experiencing complimentary and alternate therapies such as reflexology, acupuncture and chiropractic consultations. Claire was told by a chiropractor after she had an x-ray that he thought he was looking at the spine of a '*seventy year old, I was forty five at the time.*' Despite this Claire believes that using experimental approaches has prevented her from becoming a wheelchair user.

'I should be in a wheelchair, according to my GP but I've been on this diet, I do my Pilates exercise and er she (short pause) she's not erm, what's the word (short pause) she's a she's one that doesn't shock easily.' (Claire)

Claire's source of 'living life' is a determination to prove her GP wrong and be seen to be coping well through managing the symptoms herself.

'She's she's just accepted that I am doing very well because it is less for her to do you, if you see what I mean?' (Claire)

There is also an *acceptance* by Claire that '*no-one is going to knock on your door and make you better, you've got to do it.*' There was certainly evidence to suggest that Claire and the other interview participants from the fibromyalgia group were not prepared to give in though at times the emotional aspect of their pain could have impacted on their quality of life.

'What do you do with all of this [symptoms of fibromyalgia] are you gonna sit and moan and groan about it, or are you going to try and live a life?' (Claire)

Claire also suggests that even though people in the group experience similar symptoms '*we are very much individuals.*'

7.2.3 Locus of Control

In this current study locus of control was not measured formally, the data from the interviews suggests that the participants have an internal locus of control (Rotter, 1966). Evidence emerged from the data that they were likely to develop coping strategies in order to minimize, tolerate and reduce their pain and other symptoms associated with it such as low mood. The development of these strategies has been reported in the study by Horn and Munafò (1997). There was also evidence that supportive partners provided an external locus of control. However this was minimised to ensuring adherence to good techniques such as pacing and ensuring that a good diet was followed.

The participants, with the exception of Hilary, were less likely to rely on health professionals to manage all aspects of their pain (Crisson and Keefe, 1988). Claire continued to practice Pilates which she said helped with her posture while she was operating the group's telephone helpline and a consequence her pain. Jen realised that she needed to take frequent stretch breaks during her scrabble club to prevent her from exacerbating her trigger points.

David adopted pacing in order to continue with his hobby of gardening in addition he developed and stuck to a daily routine which he reported as being fragile and was put into jeopardy by his GP prescribing amitriptyline. In addition David and his partner like to take holidays in the United Kingdom. David's early retirement has resulted in adherence to a strict budget and he collects vouchers from a red top newspaper which offers holidays for £10. Holidaying in the United Kingdom allows him to drive which he views as essential because it offers him the chance to *escape* should there be an exacerbation of his pain. In addition taking the car allows him and his partner to tour

round and stop where they want to. David described scenic and natural locations as helping to distract from the pain and as a consequence elevate his mood.

'That's what you need I think with this and I think well this alright you know? I'm occupied. It's peaceful and quiet, you're walking around, you're looking at all the things, nice river, nice bridge, going over it you know? And we have (coughs) two or three hours there and then go up to [place name] that side up the coast, maybe three hours there, look around and have a sit down, come back to the car have a flask of tea and something, we always take a flask. I think when you're feeling low and that it gives you a perk doesn't it?' (David)

In their account Janet suggests that Brian has painful flare ups that begin '*right out of the blue*.' The results are that they are both unable to sleep for '*two to three nights, until it settles*.' On further questioning Janet explains that she believes that Brain's painful flare ups are caused by his diet and as consequences they monitor what he eats very carefully.

J - Well I think he had eaten something [in response to what caused the last flare up, three weeks prior to the interview]. You see I always watch what he eats, and over the years we have narrowed things down. I once got a book out of the library d'int I?

B - Yeah

J - Arthritis, rheumatoid and what you eat or something like that it was called
B - Yeah, yeah

J - and over the years we've found out, we once went out for a meal with some friends and he had cheese, potato and leek soup, loved, it thoroughly enjoyed it, Sunday morning couldn't move couldn't walk, five days it lasted. Loved tuna sandwiches, the day after couldn't walk, Flora margarine, butter, margarine ...we can only eat Clover

Brian also has contact with members of the public when his doing supermarket collections for the charity. One conversation he recalls with a male suggests that he is not impressed with how other people manage their arthritis.

'I'm surprised at how many people have got arthritis. "oh, what are you collecting for?" says this fella. "Arthritis Care." I says. "Well I've got arthritis." He says. Er well (clears throat) he gets pain [the man in the conversation], the different pains like. "So well why don't you come down [to the meetings]?" and he says "Well I don't want to be bothered, there's nothing really you can do I've lived it with it so long." No? And to me the majority of people are just apathetic about it, their quite willing to put up with it.' (Brian)

Brian and Janet's account would suggest that Janet provides an external locus of control for Brian. However, their account also revealed that Janet had an emotional breakdown as the result of caring for her elderly mother, their three young children and Brian who was becoming increasingly disengaged. Janet also needed to earn money to *keep the family going*, she had three low paid jobs and was sometimes out of the house for eighteen hours. There is a suggestion that the emasculation that Brian, who saw himself as the breadwinner, was further compounded by Janet's need to work harder. The breakdown for Janet resulted in her taking a computer course at the suggestion of her mental health worker. Janet '*took to it like a duck to water*' this was measured by her as '*after I switched in on and it didn't blow up*' as a result she enrolled Brian. This made Brian realise '*that our brains were turning to mush*' and as a consequence something *clicked* and he informed Janet that '*we're going to have to do something about this.*' At the time of the interview Brian was completing a General Certificate in Education (GSCE) in English and Janet was completing a GSCE in maths. In addition Brian began swimming to help him to move with more freedom and the computer lessons have allowed him to enjoy the internet, e-mail his family and play computer games with his grandson. He realises that he is unable to participate in physical activities with his grandson but the ability to use the computer has extended his role as a grandfather and also contributed to his quality of life.

David, Brian, Claire and Jen had supportive partners who attended the group meetings with them. Claire and Jen's partners help to run the group by setting up the room as well as staffing the group's library. The partners also helped them in successfully managing their chronic pain by legitimising their experience and contributing to their individual self management activities. An example of this is reported in David's account. His

partner attends the group meetings with him. She recognises that if David is to continue with his hobby of gardening he needs to learn to pace himself more. David acknowledges that his partner is excellent at ensuring he does not over exert himself. She insists that he rests and relaxes at timed intervals which are dependent on the gardening task. Through the provision of an external locus of control David's partner also feels that she is contributing to his self management and is supportive of his daily routine. Mary's partner does not attend the meeting as Mary believes that they are her thing. Her partner does support her and she provides him with information about her condition and suggested self management approaches the results of which are that he ensures that she paces herself.

7.3 Reasons for Group Participation

At the beginning of the interview the participants were asked the reason they had joined the support group. The responses included obtaining more information about their illness, increasing their social network, medical professional recommendation and starting a support group. These primary reasons are also reported in the chronic pain support group study by Subramaniam et al (1999). However in this current study interview participants and other group members who were not interviewed identified philanthropic reasons as a motivational factor.

The motivational factors are reported in the remainder of this section individually but the participants often reported that these are multiple or interwoven factors. In their interviews the primary reason for joining the group was spontaneously reported and a secondary reason was given later in the process. The multiple or interwoven nature of

motivation to join a support group was also reported by the participants of the Subramaniam et al (1999) study.

7.3.1 Informational Deficit

In their interviews Deidre, Mary, Jen and Jess spontaneously identified that there was a deficit of information within the formal healthcare system following diagnosis of their particular illness. This they cited as the primary reason for joining the support group.

Jen further reported with surprise that the consultant printed information for her from an internet search he conducted about fibromyalgia during a diagnostic consultation. She also reports that she was told to read a booklet provided by Arthritis Care about fibromyalgia which was available in the out patients waiting area. The dissatisfaction about the information provided in this booklet will be discussed later in the chapter eight on page 289.

The data from the interviews of Deidre, Mary, Jen and Jess also suggest that since their diagnosis, which table 7.1 (page 245) shows has been for a number of years, they have exhausted the information supplied by the formal healthcare system and it has not fulfilled their needs for a number of years. The results of this are that for Mary, Jen and Jess medical professionals are seen as peripheral characters in their chronic pain trajectories. Mary and Jen remain in the formal healthcare system attending outpatients' appointments in secondary care. They both view this as routine and only Mary talks about the other patients she meets regularly there, some of whom are members of the Arthritis group. She names this informal group the Friday club and discussed the support they give one another during their outpatient visits which for some involved

discomfort from injections of medication as well as the taking of blood samples.

Mary's interview suggests that she does not have a therapeutic relationship with her general practitioner regarding her psoriatic arthritis. She reports that she feels they do not understand her illness and that this reduces their role to that of gatekeeper for her prescription renewal.

In the support group Mary also identifies that her psoriatic arthritis makes her unique as she is the only member experiencing it. She identified that this often leaves her feeling isolated particularly in terms of discussing the irritability of this condition and the impact this has on sleep for example. During the interview Mary reacted positively to questions about the group, analysis of her interview data suggests that the information provided by the group has also impacted positively on self management activities such as pacing. At the time of the interviews Mary was the only participant working. She reported that she would be retiring the following year. Mary discussed her ambition to have an active retirement and this included participating in the challenging Arthritis course with the long-term view of becoming a trainer.

Deidre was a retired nurse but had identified a deficit in her nursing knowledge/education when it came to understanding her arthritis. In her interview she stated that this deficit was due to the lack of experience she had of nursing older adults whom she suggests are the cohort that experiences this particular illness. Later in the interview she contradicts this when she discusses a friend of her daughter who had experienced infantile arthritis. During the initial stages of her arthritis trajectory she informs me that her medical consultations were conducted by a colleague with whom she was working. She suggests that there were advantages and disadvantages to this,

primarily she recognised that her previous working relationship with the consultant contributed to her not seeking further information as professionally she felt it was not beneficial for her to declare her lack of knowledge. Deidre was also one of the first members of the group to embark on the Challenging Arthritis course.

The new member who joined the Arthritis group during my participation identified information as the motivation for her becoming a member. She was friends with another member of the group and hinted that the social element of membership was also a motivating factor. In a discussion we had about the group she informed me that it would be a positive contribution if the group could attract younger members. She also suggested that the venue that was used by the group (an older adult centre) could be a potential barrier to this, in the response she suggests that the group should organise fun activities such as treasure hunts as well as meals out rather than the same monthly meeting format.

Jess consults with a private general practitioner (GP) because this gives her more time during consultations. She recognises that her particular financial circumstances are more favourable than others in the Fibromyalgia group. Her description of the formal healthcare system suggests that she believes it is based on a '*culture of blame*'; Jess recognises that she is overweight and declares that '*I don't need reminding*'. Interestingly, Jess, despite her reporting the advantage of private medicine being time in consultations also reported that she has not received a formal diagnosis of fibromyalgia but has self diagnosed. This was after reading a book written by a clinician from the United States of America (USA) who also has fibromyalgia.

In this book I read about it [fibromyalgia] about the symptoms and I'd got every one (Jess)

The remaining interview participants discussed the provision of the information they were given by healthcare professionals in the initial stages of the diagnosis but they did not report this reason spontaneously and it only became apparent when they discussed medical consultations.

7.3.2 Social Networking

Munn-Giddings and McVicar (2006) report that the result of a perceived diminishing of a social support network is a motivational factor for support group participation.

Although this issue is more complex as the literature recognises. The diminishing of an existing support network was expressed by Munn-Giddings and McVicar (2006) as having numerous causes. These include close friends and family being unable to cope.

This results in the existing support network being unable to offer any assistance.

Additionally it is also reported that others within the social network cannot possibly understand the issues because they are not experiencing the chronic pain.

In this current study there was evidence from the interview participants' data that perceptions play an important role in the assessment of a diminishing social support network. Brian (Arthritis Group) and Alison (MS Group) identified social support needs as their motivation for joining the group. Janet, Brian's partner also wanted to increase her existing social network. This is despite Janet and Brian being involved in numerous activities on a weekly basis including church, church groups and exercise classes.

In contrast Alison recognised continually throughout her interview that she needed to increase her social network after the unexpected death of her partner. Prior to this life changing event Alison reported that she really didn't see the need in spending time with others outside the family unit and this resulted in her losing contact with her existing support network. As a consequence after she experienced the loss she found that she was very much alone and identified that she depended on her daughter to provide her with the support she needed. She also joined the bereavement support group CRUSE and met a number of people with whom she is still in contact with. She also went on holiday with another female member of the group but withdrew from this arrangement because she felt that her multiple sclerosis could potentially hold the other woman up from having a good time.

So I went with one lady [from CRUSE] on holiday every year until quite recently and when I started getting bad with my MS. I didn't want her to feel she got to be held up with my troubles. So I, I sort of put it to her I don't think we ought to go again and so I started going with [gives name of other MS group member]. So have always yeah tried, tried to push myself to do things mm (Alison)

She also withdrew from the group because she recognised that seeing the raw grief of new members was very distressing for her and did not help her to come to terms with her own situation. This would suggest that there was a time limit for membership for Alison in this group. This is very much in contrast with the MS group, where her interview data suggests that she is an established core member and is planning on being such for the long-term.

Alison's familial support network has expanded geographically in that her daughter now lives over hundred miles away but she still identifies her as her main source of support and they take a trip to a health spa for a couple of days each year. Alison spoke of this

annual event at length and identified that it gave her the opportunity to spend quality time with her daughter. She also reports that she feels positive after the event and believes that it is a combination of the reflexology, which she specifically mentions as a positive treatment, and enjoying the nostalgia and safety of being in a family unit.

Alison has a married son who lives in the same city and though she spoke of him during the interview she did not report much dependence on him. Alison remarked that he had his own family now and this was a possible reason for this lack of dependence, although Alison's daughter is also married and has a young family, which suggests that there was more of a mother daughter dynamic to their relationship. In the MS group Alison is close friends with two members who have similar circumstances to hers, in that they have both lost their partners and have children. This would suggest that Alison has found a group which could address a number of her needs, the most dominant is grief, and the second is the potentially disabling affects of multiple sclerosis which has the potential to isolate her and awaken the feeling of isolation and loneliness she spoke about with such clarity following the death of her partner. In chapter eight page 327, I report on the informal outreach programme which has been developed by members of the MS group and which Alison is a strong member.

7.3.3 Starting the Group

Claire was the leader and also started the Fibromyalgia group because she saw that there was a need for informational as well as social support. This awareness of a need has helped Claire to establish a strong and purposeful support group. The group combines a number of factors that are highlighted in the National Service Framework (Department of Health 2006) documentation and include advocacy which was strongest within this group. She formed the group in collaboration with a consultant rheumatologist to

provide information and support for others with fibromyalgia. Later the relationship broke down but I was only made aware of this during Claire's interview. During the observation of the group Claire never openly discussed this issue at the meetings. There was plenty of scope to do so as the consultant was still working in the city where the group was based and many members were referred to him.

Claire continued to lead the group without much input from healthcare professionals, in the initial stages of the group's development this was seen as problematic, in that Claire felt she lacked guidance and direction. Claire spoke frequently in her interview about the lack of support she received, however she was not referring to other group members but the medical input that she felt the group needed. The support of medical professionals in the group endeavours she reports as helping to legitimise fibromyalgia and offer members a choice of who they could be referred to within the formal healthcare system.

The lack of input from health professionals was unique amongst the sampled groups.

The Arthritis group was started by a physiotherapist who was based at the local outpatient department. Although she did not attend the meetings she still supported the group with periodic professional input. Similarly the MS group had input from physiotherapists from the MS Society and the fitness instructor was also qualified.

7.3.4. Medical professionals Recommendations

Hilary was newly diagnosed with fibromyalgia and she joined the support group at the beginning of my participation and observation of the group. The motivation for her membership was at the suggestion of her GP, he felt that she would benefit from the

support of others in similar situations to her own. Hildingh and Fridlund (2001) recognised that information about a support group given by a healthcare professional can result in a relatively high figure of participation. However Hilary's interview took place after she had attended three group meetings and analysis of the data suggests that the group was not what she expected. The location of Hilary within her own illness trajectory is without doubt the reason for her subsequent rejection of the group as a source of support. Hilary gleans the information she needs about fibromyalgia from the internet and reported that the group would be more beneficial to her if she was allowed to discuss her own particular circumstances at the meetings. The conclusion drawn from the interview data obtained from Hilary is that the decision to join a support group should ideally be a mutually agreed decision between the individual and the group. In Hilary's case this would only have been achieved when there was a level of acceptance of her current health status, this aspect of the chronic pain trajectory is discussed later on page 269. In addition, statements from Hilary suggest that if her GP had some understanding of the function of the group it would have made a contribution to the decision more equal. In her role as a nurse Hilary had experience of starting support groups for people with epilepsy and this impacted on what she perceived a support group should offer.

7.3.5 Philanthropy

In the interview data from Brian and Janet there was strong evidence of philanthropic reasons for joining the group. Throughout Brian's chronic pain trajectory he had numerous contacts with the National Health Service (NHS) including polysurgeries to replace arthritic joints as well as consultations which addressed the medical management of his chronic pain. Brian and Janet made positive comments about their

experiences of using the NHS throughout the interview recalling the name of medical consultants as well as specialist nurses who were involved in Brian's care. They suggested that the NHS had provided them with support when it was needed but declared that in the early stages of Brian's illness the information was often lacking. They only recalled one negative experience when Brian was left on a trolley for a prolonged period in the emergency department when they were seeking help for an episode of exacerbated and uncontrollable pain. In view of their overall opinion of the NHS Brian was quite clear that he joined the support group to give something back.

'When we met to the meeting they said "why you come?" we said "we had so much out of erm the" how do you say? "the National Health Service what have you, I wanna give something back'" (Brian)

Their philanthropy was also observed during my participation and observation of the group. They were usually the first people to volunteer for extra group activities such as street or supermarket collections. In addition they also donated money raised in lieu of gifts for their wedding anniversary. Their philanthropy was recognised at the annual general meeting during the observation period when they were voted onto the group's committee as fundraising officers. The philanthropic motivation was also observed amongst the members of the core group in each of the three sampled groups. In the Arthritis group, like Brian and Janet, the core members were more likely to volunteer for fund raising events such as supermarket collections and raffles. In addition Deidre also volunteered to manage a stand at the town fare which provided information on arthritis, Arthritis Care and the support group. However the group leader informed me that the numbers of volunteers were always limited to the same people from the core group.

In the Fibromyalgia group philanthropy was evident but this was through purchasing fund raising gifts such as greeting cards made by a group member. There were no street or supermarket collections organised from the national charity. Jen's son raised funds by running marathons for the Fibromyalgia group which was used to pay for the group's annual day out.

The core of the MS group raised funds for the local hospice, where until a recent dispute with the new management, group members would go for respite care. They also helped raise funds for the MS society through the sale of raffle tickets. Like the Fibromyalgia group volunteers were not sourced from the group for street or supermarket collections by the national charity.

Evidence of philanthropic reasons was also reported by Deidre who stated that in addition to seeking information she also joined the group as a way of helping other people in similar circumstances.

Philanthropy was more dominant in the Arthritis group and this benefitted the sponsoring charity. As a consequence I had an opportunity to discuss the philanthropic aspect of the group with the regional fundraiser. She recognised that there were numerous advantages to having local groups in that they helped recruit participants to the Challenging Arthritis course and increase the number of potential course leaders.

This policy mirrors current UK government policy reported in chapter 1, page 19. It was also recognised that support groups provided the charity with a steady flow of income through subscriptions and philanthropic activities such as supermarket collections, donations and sponsored events. The charity believed in the continued

existence of face to face groups even though they had invested in an online forum and this was confirmed when I was told that there was a support group expansion policy in the region. The charity was canvassing for potential group leaders in underrepresented areas of the region.

Philanthropy as a motivational factor was not reported in the review of the support group literature (chapter three). The data from Brian and Janet's interview suggests that they view philanthropy as an essential component of giving something back to society. They felt that the NHS had helped support them through the difficult aspects of Brian's illness trajectory. In addition their philanthropic reasons helped them to achieve an active retirement. This was important for Brian who was medically retired earlier than he anticipated. It was evident that Brian and Janet were a traditional family and the impact that his illness had on his normal working trajectory somehow emasculated him. The support group helped him to reclaim a sense of social usefulness. This was evident in the interview, where Janet spoke in detail about Brian's medical past. Brian spoke of the present and future in philanthropic terms such as ideas for fundraising as well as conversations he had with people whilst he was performing supermarket and street collections.

7.4 The Identification of *Three Selves* of Chronic Pain

On page 246 I reported on the comorbid illnesses that were experienced by the interview participants and their approach to self managing these. I also reported that the comorbid illnesses experienced by the interview participants from the Fibromyalgia group often impacted on a positive consultation with health professionals. Overall

reporting the comorbid illnesses helps to illustrate the level of acceptance and consequently the coping of the interview participants.

This is in contrast to the impact of the primary illness which the majority of the interview participants sought support including locating a suitable support group. The data from the interviews reflected the dominance of the primary illness and also was identified as an issue in which many of them sought the support of the sampled groups.

The interview participants were asked how many years they had been experiencing chronic pain. The result of asking this question was a narrative of their lives prior to diagnosis, during the diagnostic process up to the present day.

The analysis of the data from the interviews revealed three phases experienced during the chronic pain trajectory of the participants. This section of the chapter will explore these three phases, which I have labelled as past, chronic pain and present self. The given labels are not unlike the attitude to death and dying identified in the work by Kübler-Ross (1969) which is presented in figure 7.1.

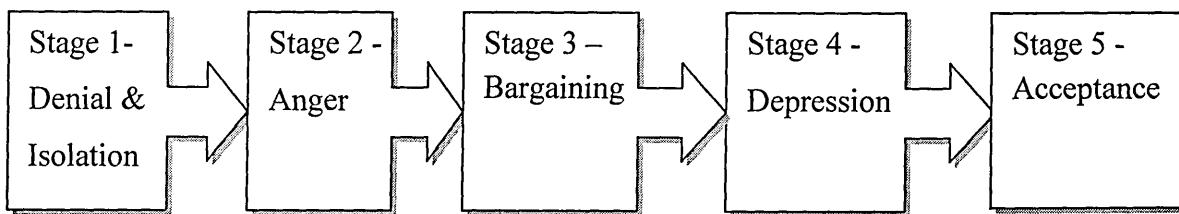


Figure 7.1. Attitudes to death and dying (Kübler-Ross, 1969)

In the Walker et al (1999) study participants reported being trapped by a system that renders them passive and powerless. There was evidence that this cultured feelings of

frustration in the participants whilst bitterness and anger lurked beneath the surface.

Walker et al (1999) identifies that anger is a salient feature of the chronic pain experience, but one which is frequently repressed. Hilary's interview gave me insight into the isolation and anger which is experienced in the chronic pain trajectory. She had achieved diagnosis eighteen months prior to her interview and as a consequence was just emerging from a self imposed isolation. Hilary's isolation is discussed further in chapter eight on page 314. Her anger is ongoing and is focused on the treatment she has received initially by her family doctor, who she had known for years.

'I didn't have this doctor then see (her present GP), it was er a husband and wife who had got absolutely no empathy, not anything, and the only answer from the doctor was to be referred to a psychiatrist (long pause) and he said to me "but the pain it is in your mind." I said "no, how can you tell me my pain?" I said "You know me from way back, you've only got to look at my notes." He says "Well you have certainly gone funny." And he prescribed me diazepam, he gave me diazepam. (Hilary)

She has since changed her general practitioner for one who she has identified as more empathetic to her circumstances. This general practitioner was the person who identified that group membership may help her. Her despondency with the system also encroached on her experiences within the secondary care setting. Where she found that her treatment further nurtured through the feelings of frustration due to the psychological label she has been given in the initial stages of her trajectory.

'A few times they sort of said "she's a psychiatric patient, she's got psych problems." No empathy, no empathy. It was quite sad really having been treated like somebody who was unintelligent, somebody who was psychotic if you like, I got all these labels, the attitude absolutely appalling, absolutely appalling. So I I I erm, I thought well where do I go from here? Nobody understands, I don't understand what this is erm. I couldn't go to the toilet, I couldn't swallow, I had swollen glands. I had everything and the pain was absolutely horrific. They took me to A and E and they said "it's all in my mind." The pins and needles just wouldn't stop. (Hilary)

She feels let down by a *system* and what has made the situation worse for Hilary is the that she has actually worked within it and as a consequence believed it was setup to help

those who are ill. This frustration with the system was identified as a theme entitled '*they don't understand*' in the study by Walker et al (1999). Hilary's severe pain is focused around her ears and mouth and as a consequence she is currently being managed by her general practitioner and her dentist. Hilary's account of her pain suggests that she is still hopeful of a cure.

Hilary's hope for a cure is in contrast to the other interview participants who reported that they were still experiencing pain but are engaged in normal life despite the sensation. This would suggest a level of acceptance (figure 7.1, page 270) which has been recognised as a complex concept in chronic pain (Walker et al, 1999; Viane et al, 2003). Walker et al (1999) has labelled the aspect of acceptance in the chronic pain trajectory as '*coming to terms*'. In the study by Viane et al (2003) there was recognition of two core components relating to acceptance of chronic pain. First, acceptance is captured by the engagement in normal life this is despite the pain. Second, acceptance is the recognition that a cure is unlikely, and to search for a cure is only to avoid engagement in normal life. Viane et al (2003) also reports that a greater acceptance of pain was associated with better mental health. In this study acceptance was also partially achieved through experience and an increased ability to self manage. In addition the participants from the Fibromyalgia group reported identical experiences in the diagnostic phase, which many reported as lengthy, to those that Hilary currently finds distressing. Claire also reported receiving a psychological label but this was some time after she had received her diagnosis and was when she had started the support group. In response Claire has identified the importance of communication with healthcare professionals as a focus for the group. This aspect of Claire's interview is discussed further in chapter eight, page 322. Differing degrees were given by other interview

participants of being disenfranchised from the formal health care system and ineffectual medical consultations. Jess described the National Health Service as nurturing a '*culture of blame*.' The aspect of delegitimisation and a need to be taken seriously by health professionals is recognised in the diagnostic process of medically unexplained illness and has been reported in the studies by Malterud (1992) and Richardson et al. (2006).

The interview participants from the MS and Arthritis groups did not report feelings of being disenfranchised or delegitimized, although Mary was perhaps least satisfied with the level of information she was given in the NHS regarding her psoriatic arthritis.

Brian and Alison reported a general feeling of satisfaction with their experiences in achieving diagnosis. Deidre felt that her nursing background prevented her from asking basic questions about her illness. However her nursing gave her the ability to negotiate her way through the formal healthcare system and allowed her some degree of satisfaction with regards to her medical management. Overall these participants described in their interviews aspects of Kübler-Ross' (1969) stage of *acceptance*.

The findings of this current study are similar to those of a recent study by Leegard and Fagermoen (2008) which recognised key experiences with patients who had undergone a coronary artery bypass graft (CABG). The study found five key experiences which are identified as the paradox of surviving alone with supportive relatives, sense of self disrupted, losses, fears and going on with life. These findings have revealed that patients' post operative experiences are not solely dependent on successful surgical treatment and early discharge from hospital. The consequences of this are that experiencing CABG is something that continues long after surgery and may be something which has a permanent influence on the individuals' life. Similarly in this

current study there were three clearly identifiable selves within the interview participants chronic pain trajectory which are the past, chronic pain and present selves (figure 7.2, page 274). The remainder of this chapter will discuss the three selves of chronic pain which were reported earlier on page 269 and were identified from the analysis of the interview transcripts in this current study.

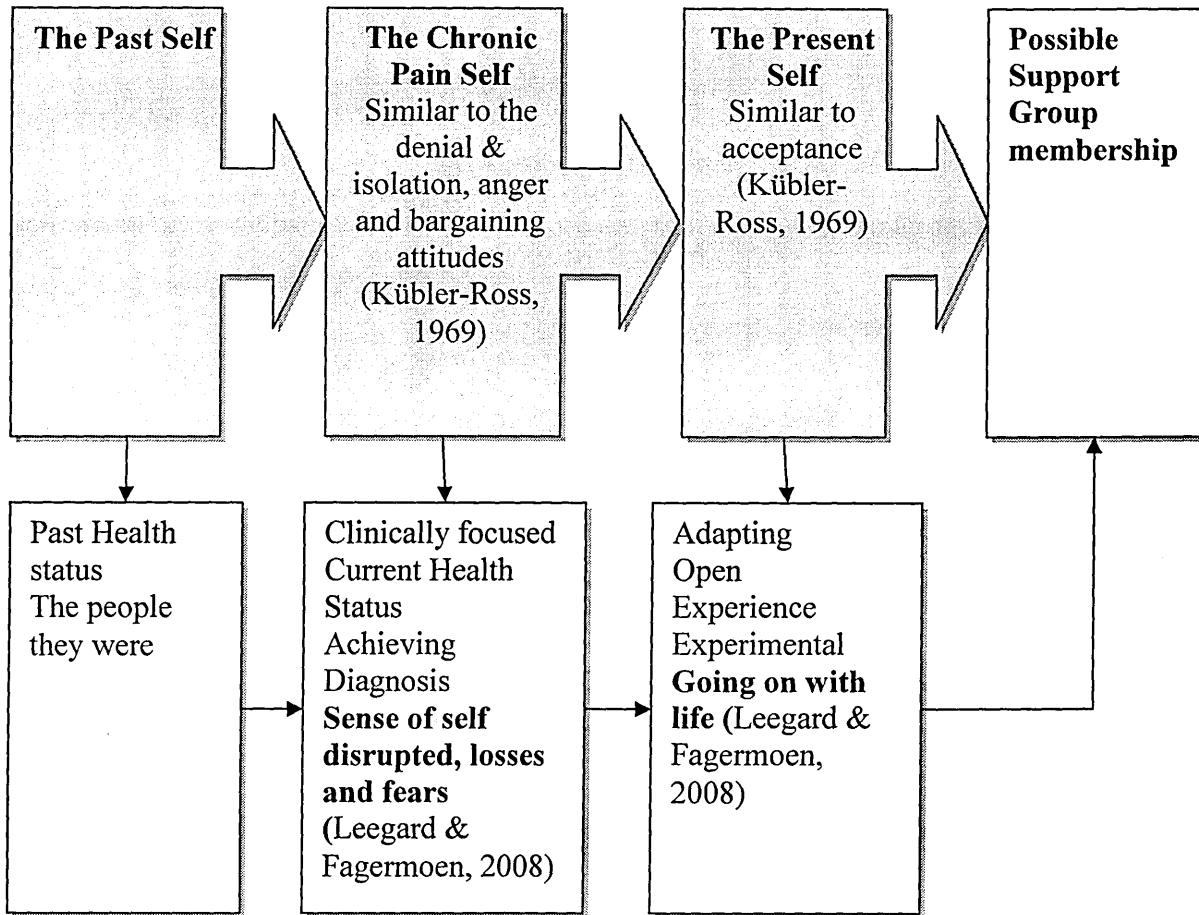


Figure 7.2 a diagrammatic representation of the three selves of chronic pain

7.4.1 The Past Self

The interview participants across the sampled groups focused on the past self but their reporting focused on differing aspects which were dependant on diagnosis and as a consequence the sampled group. Those experiencing fibromyalgia were focused on their

medical history hoping that they could identify a specific incident or trauma which may have resulted in their experienced health status. In Claire's interview she identified a head trauma from her childhood. David identified a trauma he had at work involving a heavy fire door which was prematurely slammed shut resulting in an injury the results of which were a prolonged absence from work. Jen believed that the toe amputation she had undergone had led to the development of symptoms of fibromyalgia.

Hilary's account does not report any aspect from her past medical history, the focus for her was current. There is still a hope for Hilary that a solution can be found to help her to achieve freedom from the distress and torment that she is currently experiencing. The experience of Hilary would suggest that the past self is not a resource for solutions for those who are, like her, in the chronic pain self.

Alison from the MS group developed trigeminal neuralgia and multiple sclerosis following the death of her partner, unlike those in the Fibromyalgia group she did not associate this with her health status. She focused on the person she was and reported that due to her emotional status at the time her health was not a primary concern. An example of this was when she had undergone a scan on her skull and not returned to receive the results. The focus of the past self for Alison was an idealised family unit.

Those from the Arthritis group focused more on the people they were; they used the reduction of their efficiency within the work environment as a measure of a demising health status. Brian spoke of the number of roles he had in the iron foundry where he worked when heavy labour became impossible. He was given the job as a van driver delivering to customers of the foundry until the deformities to his extremities became problematic, he was then allocated to cleaning the floor of the foundry but his pain

became further exacerbated and he was medically retired. Deidre recognised an interruption in her work as a nurse when she was unable to inflate a sphygmomanometer when taking a patient's blood pressure. Deidre also reported becoming increasingly tired. As a consequence she reduced her hours and eventually was moved to a day ward, which she reports as finding unchallenging and eventually she was medically retired. Mary was the only participant who was still working but has reported that the pain caused by her psoriatic arthritis reduces her ability to drive and as a consequence works from home twice a week. Mary reports this as a positive aspect of modern approaches to work and prevent her from having to retire early because of the long commute she would otherwise have had to do. Mary believes that the approach of her employers will allow her to *finish the race* and retire next year as she and her partner had planned.

7.4.2 The Chronic Pain Self

There was less division between each of the interview participants when they discussed the chronic pain self. The chronic pain self is defined by the diagnostic process and the focus of the individual on their symptoms and other health issues. This particular self is where Hilary is currently located and her interview data suggests that currently her life is revolving around contact with professionals. Evidence for this is provided from her interview where she provided me with the dates of when she was seeing medical professionals including her dentist and her general practitioner.

The data from the interview participants when they discussed aspects of their trajectory were almost identical. There was a focus on the how debilitating their health status had become and the relative indescribability of their pain experiences. They described how they achieved diagnosis. In the case of those with fibromyalgia the achievement of diagnosis took longer than those of Alison and the Arthritis group participants. When Claire talks to people who have been newly diagnosed on the group's helpline, she remembers the symptoms that she experienced at the time of diagnosis.

'If anybody rings me and they say "oh I only got diagnosed two weeks ago, I am scared." And all this, and I say "well look back and see how long you think you've had it." You remember aches and pains that didn't go away, even when you went to bed early.' (Claire)

Achieving diagnosis did not prevent episodes of depression which the literature highlights (Morrison and Bennet, 2006) as being a reciprocal relationship with those experiencing chronic pain. Interviewing Janet helped to illustrate Brian's sense of hopelessness and disengagement with previously enjoyable activities. She described Brian as '*a broken man.*' He rejected engagement with music and reading, activities that he had highlighted as previously enjoyable. Brian's illness had resulted in an early retirement and this was the stage that he felt that his chronic pain had disrupted his *normal* life trajectory and emasculated him as reported earlier. Janet recalled events in Brian's pain account by using significant dates such as their children's weddings, the birth of their first grandchild etc. David was medically retired aged forty three after he recognised that '*I was just a liability, I don't mean that funny you know, and activites at work could be very painful. But even at that age you don't want to pack up do you?*' He recognised in his interview that retiring early impacted on his emotional wellbeing.

'It was upsetting at the time, I had a breakdown, one thing and another with it, not a breakdown more going mentally barmy, but it suddenly hits you doesn't it when it all comes to the boil.' (David)

The focus of the chronic pain self is mainly clinical suggesting a faith that the medical profession would provide them with answers and consequently their management.

However the long exposure to the formal healthcare system revealed to the participants that there were flaws and cracks within it. All of the interview participants reported the positive and negative attitudes of medical and other healthcare professionals, their admissions to hospital and their operations. Only a minority of the respondents discussed their medications and only then did they draw on its eventual ineffectiveness as well as the side effects they experienced.

Hilary is still experiencing *the chronic pain self*. The evidence for this is located in her accounts which are comparable to the other interview participants' pain histories. *The chronic pain self* is the self that is less likely to benefit from support group membership because of the clinical focus and the continued sense of hope that a cure would emerge. Therefore seeing others who were experiencing chronic pain for a number of years could be potentially devastating. Additionally in Hilary's case the gap between the diagnosis of fibromyalgia and self is not yet significant enough to benefit from support group membership. There was evidence throughout the interview that Hilary had become a member of the group to appease her GP. This is reflected further in her decision to leave the group after four meetings as she felt it did not offer her anything of use. There is also evidence from David's interview that the *chronic pain self* is not conducive to support group membership. David was given the role of greeter in the early stages of the group's development. This role was intended to help new members to

understand the purpose of the group as well as help them to integrate. He reports when example of a young female who attended the group shortly after she received her diagnosis. The consequence of this was that she misunderstood who the group members were and therefore what the group could offer.

'We had one lass come, she was going barmy, she walked in, she thought we were all doctors, I think she come in, she and she's screaming, crying her eyes out. "I want a cure, I want a cure" and as she came in "I've got have a cure." And I says "steady duck (term of endearment in this location)and she came in the room meeting was about to start and I says "just come outside a minute, I'll have a word with you like." She asked who I was an I told her. (David)

David spoke to the woman and told her that nobody could help her find a cure and that the group was not a hospital. The explanation about the group that David gave was that the group members were all experiencing the pain but they were *making their own lives* despite it. This is further evidence that the group members he referred to were located in the *present self*.

'We are all in the same boat here, there's no cure you have to make your own life, you know, with it (the fibromyalgia)' (David)

He also told her '*keep yourself calm, you'll make yourself worse, stressed*'. The woman joined the group meeting and borrowed a book from the group's library but never returned.

The account given by Jen (chapter six, page 231) also referred to newly diagnosed members who attended one group meeting but did not return. This provides further evidence that the *chronic pain self* is not conducive to support group membership. This aspect is explored further throughout chapter eight.

7.4.3 The Present Self

The present self defines the participants as they were at the time of the interviews. The exception is Hilary who is currently located in the chronic pain self. The participants continued to experience chronic pain but their focus was less clinical. A possible reason for this is the reduction in the number of clinical appointments and for the majority excluding Mary, Deidre and Brian a move from secondary care back to primary care for their continued medical management. Brian, Mary, Deidre, Jess, Claire, Jen and David reported that the medication that they are taking has remained unchanged for a number of years. The reintroduction of amitriptyline to David's portfolio of medication on the day of his interview was a source of disappointment and will be discussed further on page 322. In the majority of cases the only contact the participants had with medical professionals was for a review or renewal of their prescription. Alison reported that she attended appointments at the multiple sclerosis clinic in secondary care but like Mary she viewed this as an opportunity to socialise with others.

There is also evidence from the accounts of Brian, Mary, Deidre, Jess, Claire, Jen, David and Alison that they are able to adapt to symptomatic situations through the effective use of medication or self management techniques. The self management techniques were spontaneously reported by the participants from the Fibromyalgia group. One of the reasons for this is the focus on techniques as well as alternative approaches to self management at the group's meetings providing members with options and as a consequence a sense of hope. Through the progression of their experience of fibromyalgia they *rank* the symptoms in the order of most bothersome.

Claire, David and Hilary highlight a disruption to their sleep pattern as a *priority* symptom. Claire relates her disrupted sleep pattern directly to the pain and reported how the rheumatologist also recognised this aspect of the illness.

He [rheumatologist] said to me "what's your sleep pattern like?" and I said cos I said to him I've always connected my sleep pattern to the pain (Claire)

David describes the inability to have good quality sleep as being the worst aspect of his fibromyalgia. On the day of the interview he had an appointment with his GP for his medication review. During the consultation he informed the doctor that the worst symptom he was experiencing was the lack of sleep. In response the doctor prescribed him amitriptyline which provoked the following conversation in the interview:

David: I say worse thing is sleep. Doctor gave me some, I've had these before, er oh god it's on there the box is that little narrow box [pointing to a small pile of medication placed in the corner of the room next to where I am sat]

I: where am I looking?

David: he gave me them amitriptyline

David's previous exposure to this particular medication evokes bad memories relating to inabilities to pursue his normal activities or daily routine. These activities and daily routines help in some way to normalise his present health status. The prospect of receiving this medication and the outcome of taking it led to bartering with the GP regarding dosage.

He gave me those again today. I said I don't want them, I said I've had 'em before it's no good to me I can't get up in the morning get me coat on get the car out or walk get paper or anything. I says it's no good to me this complaint I won't be able to get up and be active as best as I can. He says fair enough, he says we'll try a real low dose. I said what do you call low? He said well twenty five which is lowish. He said I'll give you a ten one to try for a month. So I says oh well I'll try it but I don't like idea as you can tell tablet for this thing tablet for something else its like this all the time. (David)

This suggests that David has reached a personal limit of the acceptable number of pharmaceutical products he should be taking daily. There is also a sense of disappointment with the NHS that there is a lack of new ideas. There is also evidence that combating the sleep issue and maintaining a normal routine is at times comparable to a juggling act which is not understood by professionals involved in his care.

Well in the night, if you don't get up in the night and walk about mornings a bad time. I've been up oh weeks and weeks now watching that [points to television] two or three o'clock in the morning. Then I'll doze off I'll put my feet up here, this reclines as you can see, and I can doze off here in my dressing gown and jamas and have got the telly still on two or three hours later. (David)

Hilary also reports that her lack of sleep has led to lonely nights sitting or laying on the sofa. She has adopted distraction as a method of managing this. Hilary enjoys writing poetry and reports that this creative outlet has helped combat some of the overwhelming aspects of her chronic pain.

Mary from the Arthritis group describes a scenario where the psoriasis and her arthritis can disrupt her sleep. She also theorises as to whether her medication is also in part responsible for the occasional insomniac episodes.

Don't know whether the Methotrexate is erm, I don't know whether that keeps you awake or not but I'll sleep for a couple of hours and then I wake up and then I can't go back to sleep. Course that starts me tossing and turning which then aggravates the ache that makes me skin hot so that sets all the psoriasis off itching its like OH LEAVE ME ALONE (laughs) LEAVE ME ALONE (Mary)

Mary dislikes medication to point that she avoids taking it *unnecessarily*; in this case she did not want to take hypnotics to help her sleep. The solution was discovered by accident when she started Tai Chi and is positive about the affect it is having on her sleep:

I also about March this year have started er doing tai chi and erm the thing about tai chi is it, it's exercises but it's very gentle erm and because it's, it's this vicious circle bit that if you need to keep your weight off because that puts pressure on your joints erm but you can't exercise because it hurts too much. So I, I started doing tai chi and you can guarantee on a Tuesday night when I go that's one of the rare nights that I sleep all the way through (Mary)

Mary made the suggestion to invite a tai chi instructor to the group's meeting. Although the suggestion has been made at the annual general meeting for two years, tai chi has not yet appeared on the agenda.

Some of the interview participants become aware through experience of *warning signals* prior to a flare up of their pain. In Alison's case, trigeminal neuralgia is a chronic pain condition but unlike fibromyalgia and arthritis the pain is not constant.

There is also evidence that for the participants with fibromyalgia the present self continues to look for answers. Many of these participants utilised complementary therapies to ease their symptoms. They were more likely to be experimental e.g. a dietary regime. All of the participants were more open to self managing their pain and sharing their ideas with others at the support group meetings. The participant's *present self* was the most likely in joining a support group and it is this self that is the most receptive to gathering and sharing information.

The participants were not asked and nor did they discuss their future self. There was, however, frequent reference to the pain being in some parts the consequence of their aging bodies. There was also a mention by some of their fear of having to use a wheelchair. Although the status of the self in this set of examples is not sensitive to measurements of a time scale it is a process that has been identified from the data in this

study. The shift from one self to another is dependant on factors including the psychological approach of the individual and not the illness process. David gives a good example of this which he describes as moving on from complaining about the pain, in the case of the chronic pain self which doesn't make any sense to him in his current status as present self:

Complaining about the pains and that didn't make a lot of [sense].(David)

Summary of the Participant Accounts

In this chapter I have reported the themes that emerged from the analysis of the interview accounts of older adult members of the sampled groups. The interview accounts revealed the presence of comorbid illnesses which are reported as secondary to the primary illness for which they sought the support of the group. The participants in this current study did not view other long-term conditions as bothersome as their primary illness. As a consequence of this the participants managed their comorbid illnesses with some success. This self management contributed to the perseverance in managing their primary condition.

In each of the accounts there emerged examples of psychological approaches to chronic pain such as perseverance, *living life* despite chronic pain as well as locus of control. The presence of psychological approaches to chronic pain helped in the identification of the three selves of chronic pain.

The motivational factor to joining the support group by the interview participants included a response to an informational deficit, a desire to increase their social networks, starting the group and medical professionals recommending the group. These factors were reported in the reviewed literature in chapter three. However philanthropy

was also identified as motivation and this has not been reported in the literature in chapter three. Philanthropy has an impact on seeking an active retirement as well as making a contribution to the quality of life through the redefining of a social role. The motivational factors for joining a support group were reported as being multiple and interwoven.

The analysis of the chronic pain accounts identified three distinct selves in the chronic pain trajectory. The identification of the three selves of chronic pain has also helped in the analysis of the data obtained during the participation and observation of the sampled groups such as the approach to information seeking. The aspects will be discussed further in chapter eight. The sampled groups differed considerably but there is the potential identification of a framework which may contribute to our understanding of support groups and when in the chronic pain trajectory membership of a group would have a positive impact.

Chapter 8 – Study Findings: Social Support

The aim of this chapter is to present the social support activities in the sampled support groups. In the reviewed support group literature social and informational support were reported as separate entities. In this study social support is not separated and will include the four elements (figure 8.1, page 288) of this support identified by Langford et al (1997). These four elements comprise of informational, instrumental, emotional and appraisal support and evidence of these from the observation and participation in the groups will be presented under the respective headings.

The *informational* support offered by the sampled groups and explored in this chapter includes written information, guest speakers and in-group chronic pain discussions. Additionally in chapter seven it was reported that information seeking was a motivational factor for joining a support group. Therefore the information resources given to the interview participants prior to support group membership will be reported.

The *emotional* support offered by the groups will also be explored along with the support needs of partners/carers. This section will also explore the emotional support provided or received from members outside the group meetings. The interview participants also discussed the impact that their health circumstances had on relationships with none group members.

Appraisal support was an ongoing process in the MS group due to the exercise focus of this group. There was also appraisal support observed on one occasion in the Fibromyalgia group.

Instrumental support explored in this chapter includes advice and support given to group members when communicating with medical professionals. In the Arthritis group members were funded to attend the Challenging Arthritis programme and the impact that the three selves of chronic pain had on this is discussed. The Arthritis Group also appointed a group welfare officer and the positive and negative aspects of this will be explored. The MS group was instrumental in forming an informal outreach programme and the impact this had on members will be discussed. The telephone helpline was available in all of the sampled groups but the leader of the Fibromyalgia group recognised the importance of this group resource in contrast to the other groups. The Arthritis and Fibromyalgia groups published newsletters but the infrequency of the one from the Arthritis group was seen as a deficit by the leader.

The elements of social support will be reported in respect of their influence on the self management activities as well as their impact on the members of the sampled groups. In chapter seven the three selves of chronic pain were identified. In this chapter the impact that these identified chronic pain selves had on each of the components of social support will be reported. The source data for these set of findings are the interviews, observational notes, group artefacts e.g. magazines, textual information and group newsletter as well as discussions with group members who did not participate in the interviews. This is all demonstrated in figure 8.1 (page 288).

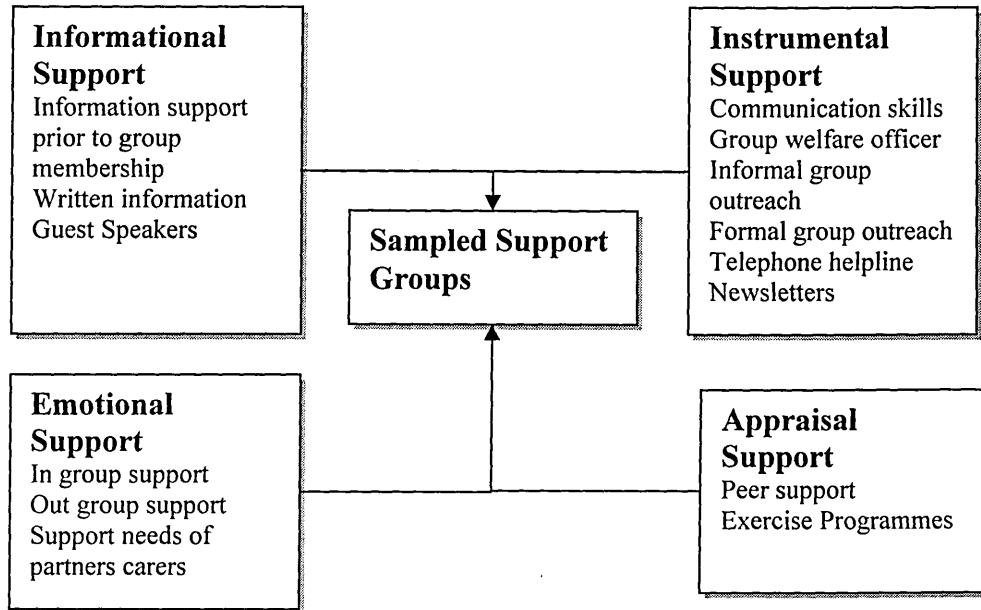


Figure 8.1 - the four components (Langford et al, 1997) of social support explored in this current study

8.1 Informational Support

Informational support provides individuals with information enabling them to deal with or actively problem solve (Langford et al, 1997). Informational support includes advice, suggestions or directives that assist the person to respond to personal or situational demands (Euphix, 2009). The literature recommends that a support group should provide informational support to members (Hatzidimitriadou, 2002). In this section of the chapter the information the interview participants received at the time of diagnosis of their particular illness will be explored. The information supplied by the National Health Service (NHS) was a question in the interview schedule (appendix 3, page 409).

This chapter will also report on the written information available at group meetings and the observations made regarding its uptake. There were a number of different formats of written information including factual as well as lifestyle and the recognition of the three selves of chronic pain helps to explain the uptake of these contrasting broadcast methods.

During the participation of the sampled group guest speakers were invited to the Arthritis and Fibromyalgia group meetings. The MS group did not invite guest speakers because of the exercise focus of the group. The choice of speaker also reflected the identification of the three selves in chronic pain (chapter seven) but was contrasting between the two groups. This is further explored in this section of the chapter.

8.1.1 Information Support Prior to Group Membership

Chapter seven page 259 reported on the provision of information prior to group membership, this will be discussed here in more detail. In response to the question (Interview Schedule, appendix 3, page 409), the interview participants were asked about the provision of the information they received from the NHS and other formal healthcare organisations. The responses from the interview participants across the three sampled groups were that the initial information they received was often authored by the charitable organisations which were also the sponsors of the groups.

As Jen reported in chapter seven page 259, those newly diagnosed with fibromyalgia are initially exposed to the written information which is authored by Arthritis Care. This is seen as unsatisfactory by many in the group.

In addition to this information Jen was also given a print out from the internet about the condition during a medical consultation in the outpatients department, which she reflected as being unsatisfactory. She felt she could have obtained this information herself and she reports that this was a further source for her particular health circumstances within the National Health Service (NHS). This aspect of her care contributed to a gradual transition from the chronic pain self to the present self when she became motivated to seek further information from a support group.

The perceived inadequacy of the information for those experiencing fibromyalgia lead to the development of the Fibromyalgia Association which is the charitable organisation that sponsors the group and others across the United Kingdom (UK). In their interviews Jess, Claire and Jen were openly critical of the information that was provided by Arthritis Care which is still in circulation. Jess described the information as unrealistic, unhelpful and had objections to the images the charity uses to portray a person with fibromyalgia.

*Jess: I mean for instance that booklet that I don't [know] whether it's still there in the rheumatology department but it's to tell you what you should be doing. Well one of them [the recommended activities] is swimming like ten lengths
I: with fibromyalgia?*

*Jess: yes well there's no way that anyone with I mean there's a woman coming out of the vertical steps in a swimming pool well I couldn't do that
I: no?*

Jess: you know there's a picture of her with a swimming hat on (laughing) you [know] an old fashioned swimming hat and you think well what's that all about cos I can't, nobody can well anybody with fibromyalgia couldn't go up those steps like that

This information has radicalised those with fibromyalgia and has developed a core theme of the provision of quality information for those who are newly diagnosed with the illness within this particular group.

The medically unexplained nature of this illness has an impact on diagnosis which is in contrast to achieving diagnosis of multiple sclerosis or arthritis for example. The results of this were observed in the discourse at the group meetings where members expressed anxiety at attending medical consultations. The impact is a loss of faith, resentment and members often expressed that they were disenfranchised within the NHS. In response Claire and Jen encouraged members to lobby their members of parliament for fibromyalgia to be recognised as a legitimate health issue and for the provision of a clinic separate from rheumatology within the NHS. This was reported within the group as the situation in the healthcare system of the United States of America (USA), where it was often seen as forward thinking in contrast to that of the United Kingdom (UK). Claire and Jen also acted as advocates for people with existing experience of fibromyalgia, as well as those who are newly diagnosed, through a series of meetings with medical consultants at the rheumatology outpatients department in the local hospital to implement changes to the provision of written information. This aspect of the group's activities will be discussed further on page 322 in this chapter.

The experience of those in the Fibromyalgia group was not unique. Brian and Janet's interview gave a historical perspective of the provision of information provided during the initial stages of his illness trajectory. Brian has been experiencing arthritis for twenty five years and Janet reported that in the initial stages of his illness there was a lack of information available in the NHS. However in contrast to the experiences of those reported by members of the Fibromyalgia group Brian and Janet now report that they feel that presently the NHS gives too much information and described some of the information as frightening.

Janet cites the example revolving around a recent consultation that Brian had at the local hospital following an x-ray on his neck. Brian's neck vertebrae had crumbled due to osteoporosis which resulted in him needing the insertion of a metal rod. They were told prior to his operation that the condition of his bone density was so severe that any sudden movement would have resulted in his neck snapping. At the time Brian was driving for the foundry where he worked having been moved from his usual occupation which involved hard labour due to his chronic pain. Janet's impression was that a sudden jolt in the van or a whiplash injury could have killed him. It was evident that the previous deficit in the information available was not a deterrent for Janet to manage Brian's increasing *disability* as best she could. She became an avid reader and selected information which would benefit self management activities such as a book she read suggesting a change in diet which could benefit Brian. Janet's summary of the information provision in the initial stages of Brian's trajectory was '*what you weren't told you read about.*'

Neither Brian nor Janet reported using any of the information that was available at the group meetings. Instead Janet draws on her own experience as a formal carer in social services as well as an informal carer for her mother. The information needs for Janet are limited to practicality and availability of devices to help her manage Brian and prevent exacerbation of his chronic pain. Brian and Janet reject the more technical information about disease progression in favour of information which will help to improve his quality of life. When Brian experiences flare ups which Janet cannot manage alone, she contacts the nurse specialist in the local outpatient department who operates an open door policy. Although the service is not available twenty four hours a day Janet said that '*Knowing they were there*' reassured her.

She described the service as being a helpful addition in the care of Brian. When the NHS trust attempted to reduce the number of nurse specialists Janet reports that the Arthritis group '*kicked up a fuss all over town.*' This led to the trust shelving the plan. Janet informed me that she felt the nurses were less like health professionals and more like friends. Brian and Janet report that if they require further specific information they use the internet. The response of Brian and Janet provides evidence that they are not clinically focused but practical in terms of their self management activities and therefore experiencing the present self.

In contrast Mary describes herself as an information sponge and this is in response to the lack of information she received during the initial stages of her trajectory. Mary's information requirements are varied and are discussed on page 296.

8.1.2 Written Information

In the reviewed support group literature it was reported that the standard of the information provided by support groups may cause harm due to inaccuracy (Hatzidimitriadou, 2002). In response the Department of Health (DoH) in the United Kingdom (UK) in 2009 launched the Information Standard (Chapter 3, page 142). However the information standard was launched after completion of the participation and observation process of this current study. As a consequence the information available at the sampled groups had not been awarded the information standard. However the MS society and Arthritis Care were two organisations that were piloting the scheme.

There was a wide range of written material available at the Arthritis and Fibromyalgia group meetings. Hatzidimitriadou (2002) identified there could be potential issues with reliability, quality and accuracy of the information available at support group meetings.

Prior to the implementation of the Information Standard (DoH, 2009) the sampled groups only provided information that was quality assured by the charitable organisations sponsoring the groups. However as previously reported this approach to quality assurance is no guarantee of acceptability by the intended audience. This was highlighted in the complaints about the fibromyalgia information written and distributed by Arthritis Care which Jess and Claire believe was written without input from those who are living the experience. This has clearly been an issue in other organisations and as such is addressed in the criterion of the Information Standard (DoH, 2009).

In the MS group, requests for written informational booklets were made to the leader the week before. The lack of the available information at the meetings or even the need for information was not discussed amongst the members. There were numerous reasons for this including the lack of new members and a reduction in the need for textual information by the existing membership. There was also a practical and logistical reason given by the leader who saw little point in setting up the room each week when people could request the information.

Textual information regarding pain and multiple sclerosis was obtained during the participation in this group. The information was authored by the MS society and discussed the biomedical influences of pain in multiple sclerosis. There were a number of illustrations which helped to demonstrate nerve pathways supporting the biomedical orientation of the information, which at times was in-depth.

The MS society also published a monthly magazine which was posted to members but not available at the group meetings. In her interview Alison spoke briefly about the magazine which is written with a lifestyle slant. This format is chosen to inform the readership through *real person narrative* about the adaptations as well as the approaches to coping adopted by people with multiple sclerosis in a number of everyday situations.

The written information at the Arthritis group meeting was displayed at each meeting, during the participation period it was observed that people rarely visited the table where the information was and only the new participant took the literature away. The reason for this was similar to that of the lack of demand for information in the MS group, there was also an established membership within this group and very few new members. This is certainly a possible reason for the lack of need for information. In contrast to the MS group though the Arthritis group was in charge of information displays throughout the town, these included healthcare locations such as pharmacies, outpatient departments as well as primary care centres. Deidre was appointed the information officer for the group and one of her roles was to ensure that the stock was not depleted in any of the chosen locations. Deidre reported in her interview that the literature which required replenishing most frequently was a book written for children regarding infantile and childhood arthritis. She believes that the book is used by parents of bored children when they visit the locations as momentary distraction and not because the incidence of infantile or childhood arthritis is particularly high in the town.

In the Arthritis group the most discussed and also popular form of written information for the group members was the monthly magazine. Copies were also available at the group meetings. The reason given for the popularity of this particular magazine was the format in which information was presented. Instead of the dry text used in other forms of broadcasting information available at the meetings the magazine featured real people who shared their experiences of living with various forms of arthritis. Articles that appeared regularly in the magazine addressed self management techniques written in the form of real person narrative and presented solutions to prevent or overcome issues. These included the benefits of adaptations and distraction such as creative writing to help combat issues of disability as this quote from Chris a seventy year old who won the Arthritis Care writing competition illustrates:

“Writing emerged as an alternative to the things I couldn’t do anymore. As parts of me deteriorated I had to give up work and painting.” (Chris, 2007 page 16)

The article also focused on the need for pacing and the adaptations that may be required to successfully engage with writing as therapy. In contrast to much of the written information skills and adaptations in the magazine are presented by *real* people in *real* situations. A male who also featured in the article experienced large amounts of pain after long periods of writing at his computer because he had not employed pacing. He then reports that to prevent this happening in future he invested in a good quality work chair and ensured that the computer screen was set at the correct level. Additionally he advocated taking regular exercise such as stopping, standing up and stretching your arms out. The article also suggested that if using a pen was difficult that there were benefits to using a computer. Another male suggests that because his rheumatoid arthritis affects his hands he becomes tired and this affects his creative flow. He manages this by only writing for a couple of hours a day. There are also regular features

in the magazine including letters from readers which covered a variety of issues regarding adaptations and self management techniques. The magazine was popular with the group members, a number of the core group suggested that the presentation of the self help articles from the perspective of real people led them to believe that there was benefit to attempting some of the techniques. The acceptance, in terms of the chronic pain selves, of the chronicity of their health circumstances is reflected in their ability to read and become inspired by others suggests elements of the present self.

The magazine also focused on news relevant to arthritis and ranged from the National Institute of Clinical Excellence's (NICE) opinions about new treatments to shortages in qualified physiotherapists. There is also a *Dear Doctor* section which advises on a range of issues from finding shoes that fit swollen feet to self management issues such as effective communications with General Practitioners (GP) and other healthcare professionals. The magazine is supported by advertising with a focus on commercially available products such as mobility scooters, chairs and over the counter pharmaceutical products.

In her interview Mary reported that one of the benefits of group membership is having a variety of information available from the magazine.

I am not sure that I would have got all those bits of information if I hadn't have gone to that support group and say articles in the magazine erm those I found useful erm in fact this, this time there was an article about psoriatic arthritis erm so I wouldn't have got that information if I hadn't have been part of that support group and joined the charity (Mary)

Mary adds that the information available in the magazine has often helped her overcome the sense of isolation she reported earlier in her interview because she was the only

person in the group experiencing psoriatic arthritis. Analysis of the data from Mary's interview suggests that the information she requires is specifically related to the need for appraisal support (House, 1981) which articles written by others in similar circumstances has helped contribute to her achieving this and as a result has become realistic regarding her own situation.

It's helped me find out more information about me condition and I think it's also helped me be more realistic about me condition (Mary)

Mary uses a combination of the factual information as well as the articles and reports that gaining information in this way has helped her to acknowledge other symptoms of her arthritis and manage them accordingly.

That's where erm I think it, it was in those books that I found erm that tiredness is a big thing about the condition er erm the percentage of people who got psoriasis that get arthritis erm that psoriatic arthritis is linked in with the inflammatory erm arthritis's erm so there's lots of useful information about and that's picked up from erm that was picked up from the support group cos they have all those booklets out so you can go and take 'em read 'em and take 'em back (Mary)

Mary also informed me that she leaves the magazine and the factual information around the house for her partner to read. She says that currently this strategy is helpful as she is reluctant to make him read things as she would not want to appear to be focused on her health as she reflects she was during the diagnostic process. Mary's reflections on her health focus during this process and her desire not to revisit or be accused of reliving it is further confirmation of the existence of the three selves in the chronic pain trajectory.

Once the magazine has been read some members chose to distribute it to others and often ask if people have old copies that they can leave in the waiting areas of their local medical practice for none group members to read. A female member also reported that

her local hairdresser found the magazine interesting and left copies in the waiting area in the salon.

In the Fibromyalgia group new members are given a welcome pack, the contents of which include information about fibromyalgia, as well as resources such as telephone help lines and websites and information for the partner/carer/family member. The packs are prepared by Claire the group leader and also include a pamphlet about the usefulness of support group membership.

The Fibromyalgia group displayed their literature and information like the Arthritis group at each meeting. However this group differed considerably to the MS and Arthritis group in that it also had a library where members could borrow books for a small fee which was partially refunded on return of the borrowed item. The library was very popular but often books were borrowed by new members who did not return to the meetings resulting in the need for replacements to be purchased. The books included reference books as well as personal biographical accounts of people who were experiencing fibromyalgia. The reference books were written for the use of healthcare professionals and a female core member of the group informed me that she read the book to prevent medical staff from '*pulling the wool over my eyes.*' The books were written by people living in the USA, which is a reason why the group was well voiced in the provision of care for people in this particular location.

The group also charged a small fee for some of the locally produced information which Claire said helped towards the printing costs. The information was seldom taken away but that produced by the Fibromyalgia Association proved very popular. In her

interview Claire also confirmed the popularity of the free literature and this she measured by the constant need to replenish the stock. Claire spoke about the locally produced information which she says was developed in response to a need for those who were newly diagnosed. Claire authored this information but it had gained quality assurance from the Fibromyalgia Association and was made available to other support groups. Claire and Jen sought to have this locally produced information stocked in the rheumatology outpatients departments at the local hospital and this explicit intervention (Euphix, 2009) is discussed in further detail on page 322. The replenishment of the free written information in primary care locations was the responsibility of all of the group members who were asked by Claire and Jen to keep an eye on stock levels in their local medical practices and also report if there was no information available in others. The group also advertised prolifically in primary and secondary care locations and the same strategy was used to make sure that group advertisements were available in as many medical practices as possible. This is an excellent strategy and was very popular with group members who were keen to create awareness of the group with others including healthcare professionals.

8.1.3 Guest Speakers

The MS group did not invite guest speakers to the meetings simply because of the exercise focus of this group. The Arthritis and Fibromyalgia groups invited guest speakers to their meetings. There was a contrast between these groups regarding the type of speaker who was invited.

In their annual general meeting in 2006 and 2007, the Arthritis Care group voted to exclude speakers who would focus on and discuss arthritis. In her interview Mary

suggests that one of the reasons for the rejection of this type of speaker is because there is lack of anything new coming from medical or other healthcare professionals.

They [the group members] are not interested in erm in having somebody talk to them er about this pill and that pill cos when, when erm [name] came along, the rheumatology nurse, I think a couple of people where going 'oh you know I don't think I want to hear all that lot again.' maybe when you live with it erm you don't need to keep hearing it? (Mary)

In the past healthcare professionals have attended but they are carefully chosen for the information they can provide as Mary explains when a podiatrist spoke at the meeting one year.

I mean some of the speakers that they have down there that talk about, like the podiatrists you know that was very useful about, you know, think about your foot wear erm cos ladies like to totter round in heels and I have to wear flats now can't wear heels anymore (laughs)(Mary)

The data from Mary's interview offered further insight into the existence of three chronic pain selves and suggests that the group membership is comprised of people experiencing the present self. This composition of the membership of this group also explains the decision of the type of guest speaker group members wanted to invite. The group voted to invite speakers who could offer practical advice on day to day issues such as home security as well as individuals who may inspire members to take up new hobbies and interests. In reality during the participation and observation of the Arthritis group only three guest speakers attended meetings. The reason for the lack of guest speakers was offered by the group leader who suggested that the timings of the meetings which were also reported as an issue for potential members to the group in chapter six page 231. Two of the guest speakers who spoke at the meetings were from the regional office, one made a presentation about the Challenging Arthritis course. The other person attended the meeting to seek volunteers for a focus group to explore active retirement. There was also a local crime prevention officer invited to speak about

personal and home safety. The remaining group meetings revolved around a quiz and very little about arthritis was discussed. The continued presence of people at the meetings would suggest that members do not have an issue with this type of meeting format. At the annual general meeting during the observation of this group flower arranging, pamper evenings (female members only) and a sight impaired man who used a guide dog were chosen to speak at meetings in the following year.

This contrasts with the ambitions for Claire that she could locate a medical professional willing to speak at a meeting of the Fibromyalgia group. In their interviews Claire and Jen suggested that a presentation from a medical professional would help to legitimise fibromyalgia. Jen suggested this would be of most benefit to the newly diagnosed. However Hilary's account suggests that the support group was not for her because it did not offer her anything of significant value. She would have preferred the group to act as a forum for members to discuss personal circumstances as a way of helping support the distressing aspects of the illness. This will be discussed further on page 304. Additionally in chapter six (page 235) Jen also reported that the majority of new members were newly diagnosed and a large number of these only attended one meeting to see others in similar circumstances. This would suggest that the pursuit of medical professionals to speak at the group meetings would not particularly benefit existing members such as David and Jess.

In the absence of a medical professional presenting at the group other complementary and alternative practitioners were invited. In her Interview Claire reported in her interview that these particular speakers were chosen because they were *sympathetic* to fibromyalgia and offered an alternate management strategy to group members. The two

chiropractors and the nutritional advisor had existing clientele amongst the core membership of the group. Other members of the group complained that often these practitioners would be of no benefit to them due to financial constraints. The nutritional advisor charged seventy pounds per consultation and although she allowed two people to be consulted together it still excluded many of the members.

One of the invited chiropractors presented research from the United States of America which suggested that there were biochemical changes within the body which may contribute to the symptoms of fibromyalgia. Observational notes made during the presentation suggested that it was in-depth and heavy going in places. An observation was also made that other members of the group were making notes. A conversation with one of these members suggested that she also found it heavy going with the remark that she wished guest speakers '*would speak in English.*' There was also confusion caused by the biomedical emphasis of the presentation from two females who wondered why a simple blood test had not been developed to help with the diagnosis of fibromyalgia.

Generally the Fibromyalgia group was focused on chronic pain with frequent references to trigger points being made. The presentation by guest speakers also revolved around pain symptoms and trigger points as this was identified as often being a challenge to the management of those experiencing fibromyalgia. They did not offer solutions on reducing the sensitivity of the trigger points but reminded the group that they were aware of the challenges and responded with offering awareness and therefore potentially *empathetic* treatment.

The nutritional advisor offered members consultations regarding changes to lifestyle that may benefit those with fibromyalgia. A small minority also felt that due to the fees charged by this person her attendance did not have relevance to the majority of members. In her presentation she gave basic advice about the foods that should be avoided. These included foods that stimulate such as caffeine along with spices such as cinnamon. There was also advice regarding the omission of starchy foods such as potatoes as well as reducing consumption of high fat dairy products. The theory behind the nutritional advice related to a study that was conducted in the USA (Koutoubi et al, 2008) regarding the sporadic blood glucose levels amongst those with fibromyalgia. In response the advisor recommended frequent snacks throughout the day of foods that would be broken down slowly such as oat biscuits and children's yoghurts because of their high protein content.

8.1.4 Chronic Pain Discussions

Specific discussions regarding chronic pain were approached differently in all three of the sampled groups.

The MS group did not discuss pain but this was probably because of the exercise function of the group and the fact that Alison was the only member who was experiencing pain (Table 7.1 page 245). When asked in interview if the group offers her support for her pain she identified the fitness instructor as an empathetic other.

He was also aware if Alison was having what she describes as a *bad* pain day and offered sufficient support so that Alison did not feel isolated. Alison is unique amongst the interview participants as reported in chapter seven (page 262) in that her grief is more dominant than both the trigeminal neuralgia and the multiple sclerosis. When

asked if she would join a support group from trigeminal neuralgia if one existed in the locality her response was that she had never really thought about it. This is further confirmation of Alison's satisfaction with the group because it helped fulfil her needs of rebuilding a social network with people in similar circumstances.

Although the Arthritis group rejected guest speakers who spoke about treatment, Deidre and Mary suggested that the individual groups (chapter six, page 238) in the meetings did discuss personal circumstances such as pain. These were identified as momentary enquiries such as 'How is your pain' but none the less Mary suggested that they were beneficial. Mary also reported that people with specific arthritis's tended to gravitate together and this she said often acted as a forum for health related discussions.

The Fibromyalgia group discouraged personal pain accounts but invited guest speakers who discussed trigger points. As previously reported (chapter seven, page 271) this is a source of frustration for Hilary who believes that in contrast to her family the group would have a greater understanding of the pain that she is feeling.

They don't feel it, or what you're feeling. They [others] go, "oh have you? Oh right then" you know what I mean? So you can't really transfer that to anybody else there's only you that knows. I mean yesterday [at the group meeting] I sat there my thumbs were hurting I was in, my thumbs, I have a lot of pain in my thumbs my neck but mainly my jaw.. I actually thought rather than you know sit there sit in "oh I'm in pain oh dear" and walking about it would be nice you know to transfer [the pain] not to transfer [the pain] under anybody but because this fibromyalgia group are there that they would understand it more but then my husband doesn't understand. (Hilary)

Hilary believes that her inability to describe and let others experience the pain sensation denies them a window into her world and this has caused issues within her family. In their interviews both Claire and Jen spoke of the impact that individualised accounts of chronic pain would have on the one hour and thirty minutes allocated for the group

meetings. This practicality of group meetings could also be a barrier to those experiencing the chronic pain self to benefitting from group membership.

Summary of Informational Support Findings

The evidence from the data obtained in this current study is that information which is obtained is often broadcasted to others in the many formats which are provided through membership of the sampled groups. Chapter seven reported that information seeking was a motivational factor in the decision to become a member of a support group. The importance of broadcasting information to a wider audience including those within their social networks is evident in the Arthritis group but recognised as essential in the Fibromyalgia group. The reason for this is to create awareness of this medically unexplained illness as well as to support others who may be going through the sometimes lengthy diagnostic process. This is a response to the memories of the interview participants regarding their experiences during the diagnostic chronic pain phase of the illness trajectory. There was also an identifiable need by participants in both the Arthritis and Fibromyalgia groups of varied and quality information which may not always be available to non-members of the group.

The decision to exclude medical and healthcare professionals from speaking at the Arthritis group meetings is further evidence of the existence of the *three selves* within the chronic pain trajectory. The results of this are that people who are experiencing the chronic pain self are less likely to benefit from membership of this particular group.

This is because of the lack of medicalised input and the availability of factual information in a variety of health locations which are the responsibility of the group.

Additionally observations of the Arthritis group, in particular the lack of new members, suggests that it is currently populated by members experiencing the present self within the chronic pain trajectory. Further evidence of this is seen in the popularity of the lifestyle magazine and the apparent redundancy of the factual information because it provides nothing new.

In contrast observations of the Fibromyalgia group reported the number of new members at each of the group meetings. Jen reported that the new members were often newly diagnosed and were described as none returners, which is a reflection of their location of the chronic pain self within the chronic pain trajectory.

In chapter six it was reported that many of these newly diagnosed new members wanted to see other in similar circumstances. This may reflect the unexplained nature of this particular illness and the distress this may cause.

8.2 Emotional Support

Emotional support is described as providing encouragement as well as enhancing self esteem (Tolsdorf, 1976; Barrera and Ainley, 1983). Emotional support generally comes from family and close friends and is the most commonly recognised form of social support. It includes empathy, concern, caring, love and trust (EUPHIX, 2009)

8.2.1 In-group support

Emotional support provided by each of the sampled groups differed. However, there were some constants across the group such as outreach programmes developed in response to isolated members.

In the Fibromyalgia group emotional support was not easily observed and this was due to the format of the meetings which revolved around the invited guest speakers. This *classroom* type format prevented individual conversations during the meetings and this were left until break times or at the end of meetings. In addition it was observed that group members tended not to gravitate to the same place at each meeting. They also did not sit with the same people at each meeting. The results of this are that the formation of networks within the group was difficult in comparison to the MS and Arthritis groups. There was less regular attendance at this group because a number of the members were working.

The Arthritis group's response to the emotional needs of its members was formalised with the appointment of a welfare officer. This appointment is a requirement of the group constitution devised by Arthritis Care if the membership of a group was greater than thirty members and will be discussed further in instrumental support page 321.

The sampled groups also offered support that was less formal through the establishment of friendships because of regular attendance at meetings. As I have previously reported (Chapter 7, page 259) core members of the Arthritis group were frequently observed to gravitate to the same tables at each of the observed meetings.

Mary explained that for many, these groups offered them emotional support, she helped to identify that people experiencing similar arthritic conditions such as rheumatoid tended to group together. This she believes helps them to discuss specific aspects of their type of arthritis as well as offer emotional support. Mary also suggests that for some in these small groups the deformities of their fingers was a further source of distress because it often challenged eating and drinking which was a crucial element in the opening of the meetings were hot beverages were served with biscuits. There was also the Christmas gathering which revolved around a buffet. The expressed distress has the potential to challenge the stigma of the deformities when eating and drinking in front of people who are not living the experience. The results of this are confirmation of a form of unexpected tribalism in that it was seen as lessening distress rather than closing the group to new membership as reported in chapter five page 200.

The outcome of the relatively small number of members who attended the meetings held by the MS group allowed the group leader to talk to individuals on a one to one basis at the beginning and end of each meeting. However these conversations were open to everyone especially if the discussions were regarding the health of absent members. She also updated or enquired to those in the informal outreach group (page 327) about the progress of those who were experiencing symptomatic flare up. She also reported news from the MS society which was seen as inclusive by members who cared deeply about the organisation.

8.2.2. Out group support

The accounts by the interview participants identified elements of support amongst group members that was outside the meetings.

In chapter seven (page 259) I reported that Mary described *informal meetings* which were held in the outpatient department on Fridays when some members attended for appointments. Mary named this group the *Friday Club*. She suggests that this makes her appointments more tolerable and recognises that this is another positive element of support group membership.

There was no evidence of informal meetings in the Fibromyalgia group and David suggested that one of the reasons for this was geographical distribution of members across the city. He also believes that the nature of fibromyalgia impacts on motivation which can reduce an individual's social life. In David's particular circumstances the establishment of a daily routine does not include visiting others. The reason for this is that he reports the need for an escape route if he should experience exacerbation of his symptoms which he finds easier to do in the presence of his partner rather than others.

The MS group was far more likely to socialise outside the group meetings. Alison informed me that she met with others from the group frequently and had also holidayed and planned future holidays with two other members who were also alone. There was evidence that other members of the MS group socialised despite their limited mobility. The MS and Fibromyalgia groups were located in the same city and members from each lived in a wide geographical area. This appeared to be less of a barrier to the MS group than to members of the Fibromyalgia group. The small regular membership gave the MS group more intimacy than the larger membership of the Fibromyalgia group, the results of this were that social networks were easier to nurture in smaller groups.

There was also a greater risk of immobility with members of the MS group, many of whom were wheel chair users, therefore the need to invest in a social network is strongest in this group as method of preventing future risks of isolation.

8.2.3 Relationships with non- group members

In the literature Victor et al (2005) recognised that those experiencing chronic health problems, disability and depression have increased rates of loneliness. An increase in loneliness was also recognised as a motivational factor for group participation in the study by Subramaniam et al (1999).

Jess, David, Alison and Hilary reported in their interviews that their particular circumstances had impacted on the relationships they had with people outside the group. Mary and Brian from the Arthritis group also reported on how the impact of their illness had altered relationships with others.

Data from the interviews suggested that their illness is often questioned by others in their existing social group, this is particular the case for participants from the Fibromyalgia group. This experience is probably further compounded by the medically unexplained nature of this particular illness. The array of symptoms experienced by those with the illness is identified by Claire as offering a challenge when explaining to medical professionals.

Someone with with fibromyalgia you're your doctor running to with big long lists all of what's wrong with you. (Claire)

There is also the potential issue of lack of awareness of the existence of fibromyalgia amongst the general public. The impact for Jess is a perception that people in her existing social network may question her health issues.

*I: How are your friends, you know friends out of the group?
Jess: I don't tell 'em
I: don't you?
Jess: no not unless they ask (short pause)
I: so you just tell them that you've got aches and pains in your legs or?
Jess: well I don't think, I don't think they really notice to be honest*

Jess is not alone as David also reported similar strategies amongst his social network so that he can continue to be judged as himself and not his illness. This provides further evidence of the removal from the clinical focus identified as a characteristic of the chronic pain self.

*I've got it you know its bad but I don't want folks saying poor thing you know?
Don't want that it makes it worse (David)*

The results of this strategy for Jess is that she has either become completely removed from, or reduced contact with people in her social network. Jess tends to pair up with people outside of the group who she perceives as being in a worse health state than she currently is.

*I actually have two, I have two friends and he's, he's, he's a bit disabled as well with. We have been with them but I wouldn't er erm what's word am looking for? I wouldn't er approach the subject of going with anyone else so therefore they wouldn't know would they? Because it only erm hampers them don't it? Most people I don't [tell]
But I mean we were lucky with these friends cos you see she's not well she's a bad back but and he's pretty, pretty bad on his legs in fact I'm better than he is to be honest at walking. So really that weren't too much of a problem you see erm so we did go to Bridlington with them for the day. (Jess)*

Alison views the MS support group as a protective environment where she does not have to explain herself in contrast to her experience at CRUSE reported in chapter seven (page 262).

In addition to her grief and her multiple sclerosis she also experiences trigeminal neuralgia the consequence of which has previously been perceived by her as misunderstood by others.

I think people wondered sometimes [about the severe headaches] and they used to and er they've probably said to me erm "oh I've got headaches". Perhaps they think "she's been a bit of a misery". But it is horrible. (Alison)

How external others see Alison is important to her because of the need to establish herself socially. The results of this are that she has adopted a strategy of an open and happy image, which she reports as not being her true self.

I mean even now when you're feeling so rotten er or anything er you come home and you think. People say to me "oh your always smiling you know you're, you're, you're all you're fine you know" and I do outside I put an act on (Alison)

A diminishing social network is reported in the studies by Subramaniam et al (1999) and Munn-Giddings and McVicar (2006), they suggest that the network is disrupted by those who are not experiencing the chronic pain. The reason given is that these individuals do not know how to cope or offer assistance to the person in pain. In this current study the analysis from the interviews of Alison, David and Jess contrast this finding because these individuals have decided to disconnect from people they see as being unhelpful. In addition David's interview revealed that he is less likely to discuss his health situation when he is asked directly by others, preferring to allow his partner to do it. He avoids the serious nature of health discussions with male friends by using humour as an avoidance strategy.

When I meet anybody and they ask me how I am I just let the wife say something if the husband's there I start joking with him you know I can't I don't want to talk about it . (David)

David's approach to discussing his health circumstances began when he was told by the rheumatologist that he had fibromyalgia which is discussed further on page 324.

Brian and Janet talked about their neighbours and how they have offered support such as an occasion when Brian fell, she could not pick him up and she enlisted the help of neighbours. The point about Janet and Brian's neighbours was further illustrated during the interview when the women next door came round with Janet's washing because it had begun to rain. Janet also discusses a friend they have who is also experiencing arthritis but his approach has been different to that of theirs.

We have a friend who's got arthritis and I mean the day he was diagnosed was the day he gave up work and he never worked since (Janet)

8.2.4 Support need of Partners and Carers

Partners/carers were welcomed at the meetings of both the Arthritis and Fibromyalgia groups. The exercise component of the MS group was the reason why partners/carers did not attend the meetings. Although it may help with compliance of the exercises at home the weekly meetings at this group was felt to maintain levels of fitness by the members.

David felt that attendance by his partner at the Fibromyalgia group allows her '*to meet other folk as well.*' Giving the group a social element for partner and carers instead of just illness focused. Further studies may also reveal the presence of selves within the trajectory of carers/partners who support those with chronic pain but in this study only Janet and Brian chose to be interviewed together. David's partner declined the invitation due to work commitments. Brian's partner, Janet reported that she enjoyed the social element of the Arthritis group but often they were observed in the meetings sitting at the back of the room on a table on their own.

Hilary attends the support group meetings with a long-term friend who is also experiencing fibromyalgia. Further analysis of the data from her interview does not suggest that Hilary and this friend act as a source of support for each other. However Hilary does suggest that the friend has been diagnosed a number of years and is also experiencing other health issues. When Hilary withdrew from the group the friend continued to attend, suggesting differing locations within the chronic pain trajectory.

Hilary's interview gave an insight into the frustration and the isolation of her chronic pain self which has resulted in depression further compounding her emotional wellbeing. The frustration was identified by Hilary as the inability to explain the distress and torment that she is experiencing to her partner as well as her children. In the first year of her diagnosis and exposure to the chronic pain she cancelled Christmas. Her adult children called round to support their father but Hilary refused to come out of her bedroom until they left. She is amazed at how the illness continues to impact on the communications between her family and her partner. Through this frustration and Isolation Hilary has turned to poetry to express how she feels but she does not share this with anyone. There is a suggestion that there are elements of embarrassment at using this creative outlet.

He says I'm sorry Hilary but I can't feel it for you. You know what I mean? I can't do anything and he gets frustrated and I actually thought that we could voice things, I mean, I write and you might think I am crazy there, I write poetry (Hilary)

Hilary's partner has witnessed the pain behaviour she displays during a painful flare up but she suggests that this is not a true expression of the way it impacts on her.

My husband expected that because (coughs) he knows, he knows the pain I have been in. The times I've walked the floor, the times I've not gone to bed, times I've laid here at night cos the pain in my neck and my head. I can't explain it to anybody. (Hilary)

Hilary openly reported that a combination of the inexplicable painful flare ups she was experiencing and the anger and frustration she was feeling at not been able to communicate this with the people she shares her life. Their inability to help her and the perceived lack of support from healthcare professionals resulted in her deliberately overdosing on analgesics.

Oh I thought what is happening? And every time I sat up pain from my head all the way down. I got an emergency appointment. My husband got me an emergency appointment and the doctor said "oh what we going to do with you?" You know? I thought well what are you going to do with me? I mean things like that because I was getting a negative response from doctors and not and they couldn't find anything in the hospital. I thought well is this how I've got to live and then in one irrational moment it was just one irrational moment I took an overdose...just one irrational moment (Hilary)

The consequences of her deliberate overdose have allowed her to review sources where she obtains support which is not located in the formal healthcare system because of the perceived *double label* she has been given.

*Hilary: and I said to my husband I mean I think this is why you know as soon as I took the overdose it think I was I got a double label on there I was mad then but I realise now why people do that
I: do you?*

Hilary: yes because that was totally out of character for me and at the end of the day and I look back on it. It was stupid I'll say that myself but I wasn't rational at that time, nobody was listening at that time, I was in pain I was taking pain killers and it wasn't doing me any good but I think most of all the lack of support.

In her interview Claire accused a medical professional as labelling her as '*crackers*'.

This aspect of labelling may have helped Hilary to understand the experiences of others in the group and prevented her from feeling the group did not offer her anything of use.

During the observation of this group a female member informed me that she had attempted to take her own life on numerous occasions. The results of this were that she was on '*suicide watch*' and as a consequence she was now on a weekly prescription in an attempt to prevent her from stock piling medication.

Hilary reports that her general practitioner and dentist are now managing her care which has left her feeling that she has more support because they are empathetic towards her. There is also a slow reintroduction of her role as a mother and a grandmother within the family unit but this is still not recognised by Hilary as a source of emotional support. In her interview Hilary was looking after her young grandson and her pride and competence were illustrated through her interactions and discussions about his achievements. She recognised that looking after him would have been impossible six months prior to her interview.

Hilary's potentially tragic response to her uncontrolled pain has impacted on the trust within her existing support network. She spoke of a recent conversation she had with a neighbour who she had known for twenty years and she suggests that she spoke to her '*as if I am going mad*'.

yeah yeah or being patronised this is part of it you know being patronised, I mean even my neighbour started talking to me like this [putting on a patronising tone] are you alright? You know? and I said to I said to my husband am I going mad? Am I really going mad? Have I got dementia or something? I didn't know what to think (Hilary)

Claire also reported an episode during a medical consultation when the doctor's tone changed and he began to speak to her in a way which Claire reported as patronising. The labelling of individuals with medically unexplained illnesses has been reported in chapter two, page 42 in a study by Malterud (1992).

'He went off and when he came back he was totally different with me he was off hand he was patronising and he was er er unkind and what he said to me he he he went he came he came in and he said this is what he did [placing hand on interviewer's shoulder] "you are mentally ill and I think you have mania, do you know what mania is" and I says "oh yes I know what a manic depressive is" I says "but that's not me." He says "You are mentally ill." He says "and I am going to get you hospitalised."

Hilary's gradual reintroduction of her role within the family unit is recognition that excluding herself was harmful. In her interview Hilary discussed each of her grown up children with pride focusing on their intelligence and their careers. The recognition by Hilary of the harm of the self imposed isolation she chose could be a gradual transitional step from the chronic pain self to the present self. There is further evidence of her transition between the selves in the sources she is now using to obtain information about her health. Hilary spoke about a forum for people with fibromyalgia on the internet. The anonymity associated with these forums allows her to feel safe in expressing her concerns. The inability to do this in the face to face group was highlighted as a major dissatisfaction. Hilary's account is peppered with examples of the loneliness and isolation she feels during a chronic pain flare up which often occur late at night and the open access to the forums is seen as a source of support. In addition Hilary recognises that the forum allows her time to express herself which she recognises as not possible in either the GP consultations or the Fibromyalgia group.

Summary of Emotional Support Findings

The Arthritis group appointed a welfare officer in response to the number of members and the group constitution. Mary also reported that there was support within the group as members with similar arthritic conditions tended to group together. There were other examples of emotional support identified in the data from Mary's interview such as the Friday Club at the outpatient department of the local hospital. This was reported as being a positive aspect of membership of a support group. The small number of members of the MS group made the emotional aspect of social support easier. Further evidence of this is presented in instrumental support in this chapter on page 321.

The Fibromyalgia and Arthritis groups welcomed partners/carers to be members. This impacted on David's self management activities. David also reported that members of the Fibromyalgia group tended not to socialise outside of the meetings due to the geographical location of members.

The impact of Hilary's experience resulted in her withdrawing from her natural support network which exacerbated further feelings of isolation and depression with potentially tragic consequences. Following from this was a revaluation of her circumstances and a gradual reintroduction of her familial roles. The data provided Hilary's interview also helped to identify a gradual transitional period from the chronic pain to the present self which was reported as the identification by Hilary of where was appropriate for her to seek emotional support with reference to the point in the chronic pain trajectory.

A number of the interview participants spoke about how their illness had impacted on their existing social network. There was evidence to suggest that in Alison's case this had resulted in her establishing stronger bonds with people from the group. David and Jess from the Fibromyalgia group described choices they made of who to tell about their illness. Jess also began to assess the health of people from her existing network and preferred the company of those who were in *similar or worse circumstances* than herself.

8.3 Appraisal Support

Appraisal support is described as helping individuals to evaluate the impact of their personal circumstances e.g. the availability of personal coping resources (House, 1981).

The information is often evaluative and can come from family, friends, and co-workers and of relevance to this current study, community sources (Euphix, 2009).

Appraisal support was an ongoing process in the MS group and one of the reasons for this is the exercise focus of this group. The fitness instructor devised an exercise regime that was repetitive, the idea being that the members of the group could continue exercising between meetings. The male members of this group were the most likely cohort to respond to this component of support. Alison did not exercise between group meetings but went swimming on a weekly basis. Her ability to continue to exercise was important for her and she suggested that attending this group has helped to appreciate the importance of regular exercise.

Appraisal support was observed on one occasion during participation of the Fibromyalgia group meetings. A younger female member participated in a demonstration of holistic massage given by the guest speaker. It was clear throughout that she was experiencing considerable pain from her posture, being guarded and tense as well as her facial expressions. As a consequence she became distressed and emotional which resulted in her reporting to the group that she could no longer go on the way that she was. Her pain was described as extreme and unpleasant the impact of which was a reduction in her independence measured by her ability to continue with activities of daily living especially self care. Her teenage daughter helped her to dress and bathe. Members of the group came forward to physically comfort her and offer explanations of their reduced activities. They offered practical advice relating to her walking aids which a number of the group had noticed were not set at the right height for her.

Jen explained that the walking aids the woman used were not set correctly and this would not help her pain. Claire also explained that she had noticed that the woman's posture was not correct and she explained that Pilates may offer some help to her.

Appraisal support can be an important aspect of support group membership and was not specifically reported as a component in the reviewed support group literature. In the study by Schwartz and Sendor (1999) it was reported that altruistic actions may have an impact on the physical and psychosocial well being of an individual. In their study those who were trained to provide compassionate, unconditional positive regard to others had pronounced improvement to their own confidence, self awareness, self esteem, depression and role functioning.

Summary of Appraisal Support

There was less evidence of appraisal support in the sampled groups and this may be that this type of support is offered in private conversations amongst the group members. However the examples from the MS group provided strong evidence that appraisal support was available in support groups. Additionally the culture of the Fibromyalgia group suggests that this type of support was the responsibility of all the group members. In contrast in the Arthritis group, appraisal support was reported by Mary as strongest in the individual groups who sat at the same table.

8.4 Instrumental Support

Instrumental support is defined as the provision of resources to remove or reduce the stressful situation e.g. sharing the burden or providing goods and services or financial aid (Langford et al, 1997).

Instrumental support is the most concrete direct form of social support, encompassing help in the form of money, time, in-kind assistance and other explicit interventions on the person's behalf (Euphix, 2009). This component of social support is not reported specifically in the reviewed support group literature in chapter three. However there was evidence of instrumental support in the sampled groups (figure 8.2). Instrumental support also had elements of the emotional component of social support.

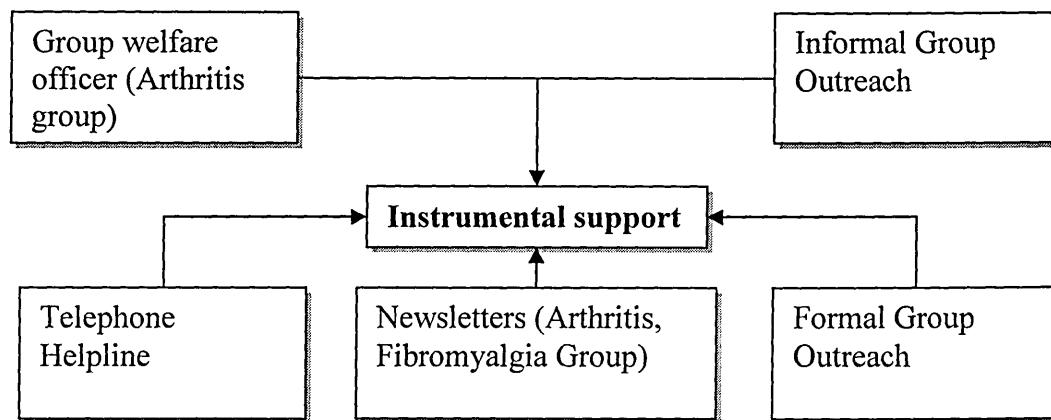


Figure 8.2 - instrumental support provision in the sampled groups

8.4.1 Communicating with Medical Professionals

Communicating with medical professionals was an example of explicit interventions (Euphix, 2009) and this was seen as priority by the leader of the Fibromyalgia group. Claire believed that by being visible in the local rheumatology outpatients department she created awareness of the need for quality and appropriate information. There was concern by Claire, Jen and Jess that those who were newly diagnosed would be given the *inadequate* information written by Arthritis Care . In response Claire and Jen lobbied consultant rheumatologists and the success if this approach was reported in the group's winter 2008 newsletter:

Dr [name] was very impressed with the yellow flyer for the newly diagnosed; the blue booklet for the patients, the booklet for the medical professionals and my Pilates report. He thought they were excellent. He informed us that after reading our informative booklets, he went straight out to the display in the Rheumatology Department and withdrew the ARC booklet. He agreed that this booklet was unhelpful to FMS patients and ours would replace it, after speaking to his colleagues.

Claire reported in her interview that the most important advice she could give a person experiencing fibromyalgia is how to communicate with medical professionals. During the participation and observation of this group, members would talk about their experiences at the local outpatients department. Outpatient appointments were viewed by many group members as challenging and negative due to the limited amount of time they had in consultations. Claire feels that it is important that individuals use their time in these consultations effectively by constantly updating their medical history as well as writing down the dominant bothersome symptoms. In her interview Claire suggested that people experiencing fibromyalgia often feel frustrated when trying to locate a sympathetic health care provider:

You can be like a bargain shopper with this condition. You can say "oh he doesn't understand me, have got to find a doctor that knows what he's talking about." So you leave and you go to another one and all the same things are there. You know it, it seems to be a problem all over and there are very few that have a good GP that will take the time and listen to them and but most don't want to know (Claire).

The frustrations of affective communications with healthcare professionals is reported by Malterud (2000) and Richardson et al (2006) chapter two, page 42. The bargain shopper analogy helps to illustrate this further and has comparisons to the examination and re-examination and identification of healthcare professionals who issued reassuring answers reported by Kübler-Ross (1969, page 33).

David, as previously reported spoke of his frustration at the ineffectiveness of consultations with his general practitioner (GP). David uses guillotine humour to help him cope and deal with his circumstances. Analysis of the data from his interview suggests that this was not always appreciated and this was apparent when he received the diagnosis from a rheumatologist, even though David recognises that this is his personal approach to receiving bad news.

'He said "You have got fibromyalgia." I said "Do you drink or do you eat it, you know like I'd never heard of it." And he said "Don't be funny, it's not a funny complaint." I says "it's just one of them things, frivolity."' (David)

David explained that his approach to receiving the *bad* news resulted in the prognosis for his diagnosis was discussed in a sombre and '*worst case scenario way*'.

'He says "you are going to be in a lot of trouble with this a lot of pain" and he says "there is no cure." So I says "fair enough, if I've got it I've got it. I've got to live with it."' (David)

David's interview suggests that he is not always comfortable discussing his health even with medical professionals and this manifests in either humour or negotiation. An example of this was that there was a genuine annoyance when he spoke of the consultation he had attended on the day of his interview. His main concern was that the GP focused on the secondary illness and his fibromyalgia was barely discussed. He also complained that medication, in this case the tricyclic antidepressant amitriptyline, which is often prescribed for those experiencing chronic pain, had a profound effect on his daily routine and as a consequence his quality of life. However he believed that attending the group meetings and talking to others in the group reduced the isolation he previously felt. This resulted in the development of effective negotiation skills which he implemented during the consultation and as a consequence came away with a lower dose of the drug.

The Fibromyalgia group was unique in that it discussed affective communications with medical professionals. The medically unexplained nature of the fibromyalgia (Richardson et al, 2006) and the group members' own experiences offer explanations for prioritising this.

The Arthritis group helped members to participate in the Challenging Arthritis course which has communication with medical professionals as a module (Barlow et al, 2000). However in the MS and Arthritis group meetings communicating with medical professionals was not discussed. This may be due to the recognition of both these health issues within the formal healthcare system.

8.4.2 Challenging Arthritis

The Arthritis group was the only sampled group to offer this course, they had been successful in obtaining a National Lottery grant in 2006 which was used to provide free places on the Challenging Arthritis course for group members. At the annual general meeting in 2007 it was agreed that further funds would be raised to continue to offer the course to others in the group. During the participation and observation of this group funded places were given to four members, including Deidre, to attend. Mary felt that this was her goal for her retirement but unlike Deidre she felt she wanted to take it further and become a trainer.

Offering funded places on this course was popular and there was a waiting list. I have reported that the membership of this group comprised of individuals experiencing the present self. The conclusion from this is significant because in chapter three, page 117 it was highlighted that there was a large drop out in these types of courses.

Additionally self management courses were described as expensive with little engagement following attendance. The reason for this could be that candidates are selected at the wrong location within their trajectory and engagement with a self management course can only be achieved in the present self. Further evidence is provided for this with those that have attended the course from the Arthritis group. These individuals often spoke positively about their attendance and shared with other information that they acknowledged as not knowing before. In her interview Deidre reported that she had found the intensity of the six weeks difficult but overall she had enjoyed the experience and more importantly had identified its usefulness. However at the time of her interview Deidre identified the tiredness as having an impact on her decision not to become a trainer at this point in her trajectory. This is in contrast to Mary who identified the role as a trainer as a goal to fulfil her need for an active retirement. This was also a continuum of her current role as a trainer in local government.

8.4.3 Group Welfare Officer

The group welfare officer was appointed at the annual general meeting observed during the participation of the group. The group leader was not sure why the constitution stated this. The regional office suggested that the role was developed to prevent isolation and to maintain connections with the group particularly in less urban areas as well as areas with a more transitional population such as London. However this group was located in a town surrounded by rural villages and the appointment of the welfare officer seemed to be more a badge of honour than a necessity. This conclusion is drawn in the direct comparison with the informal outreach programme in the MS group (page 327) which gives all group members the opportunity to become involved. Additionally the MS

group is located in a larger geographical area incorporating a city as well as rural communities.

The welfare officer's primary role is to act as a liaison between the group and members who had not attended a number of meetings. The welfare officer would visit them and ask if there is anything that the group could do to support them. A regular update regarding the person's wellbeing would be given. The welfare officer would also ask the person if they were able to take visitors or 'phone calls, this was also fed back to the group.

8.4.5 Informal Group Outreach

The MS group was the only group to have an informal outreach programme the possible explanation for this has been identified as the potentials of reduced mobility for people experiencing multiple sclerosis. Alison was instrumental in implementing the outreach programme and she identified in her interview that being part of the programme has '*helped me to feel less alone.*' Additionally in her interview Alison thought that the informal outreach programme was a positive aspect of group membership because it allowed her to help others. Elsewhere in her interview she also suggests that without the programme '*I would be sat waiting around for the next meeting.*' This is despite being occupied with other activities not associated with the MS group in the week. In chapter seven page 262 it was reported that Alison had a sense of belonging and safety with her membership of this particular group.

In contrast to the Arthritis group the size of this group did make it easier to be aware of members who had not attended meetings on a number of occasions. Alison also described in her interview that visits to isolated members extended to members of the individual's family. One individual's mobility had declined so much that they were unable to visit their elderly mother but Alison reported that she and the others decided to do this on their behalf. The establishment of the informal outreach programme provides further evidence of the role of philanthropy as a motivating factor for joining and maintaining membership with a support group.

8.4.6 Telephone Helpline

Claire the leader of the Fibromyalgia group was a qualified counsellor and hosted a help line where group members could discuss issues with her. In her interview she identified this as an essential component of leading the group. Claire reports that a majority of isolated group members contacted the helpline '*just to chat*'. Claire also reports that she also communicated by letter to six isolated group members, this method of instrumental support is not reported in the reviewed support group literature in chapter three. Claire reports that the members who receive letters are very positive about this approach. She believes that communication via telephone for prolonged periods can exacerbate the trigger points because often members remain in the same position during the conversation. She drew on her knowledge of Pilates to prevent lengthy telephone conversations exacerbating her pain symptoms by using a gym ball to maintain a correct posture.

Claire reported that there were currently around twenty four isolated members and the majority of these individuals used the helpline. The telephone used for the helpline is located in Claire's spare bedroom which has been converted into an office. The consequences of having the telephone help line in her home was initially problematic as she felt obliged to answer the 'phone at anytime. There is also an issue again with the medically unexplained nature of fibromyalgia in that for some people their symptoms suggest that they may have other life threatening illnesses.

'You've got to adapt to each situation when they ring in or out when some people ring up and their so distraught they think they've got cancer' (Claire)

Staffing the group's telephone helpline constantly had a serious impact on her emotional health and resulted in her having a '*nervous breakdown*.' The helpline is now in operation during office hours but Claire regularly checks the voicemail for urgent calls.

In contrast the leaders of both the Arthritis and MS groups did not report usage of the helpline by isolated members. The MS group leader informed me that her partner staffed the helpline but the number of calls had reduced significantly to only one or two calls per month. These calls were usually regarding membership and meeting times of the group.

The leader of the Arthritis group staffed the helpline with his partner and reported that usage of this facility was mainly by core members who wanted to share with others in the group *health bulletins*.

8.4.7 Newsletters

Newsletters were written and distributed locally by the Arthritis and Fibromyalgia groups. The MS group's newsletter had been abandoned a year prior to the observation of the group.

The Arthritis group published at least one newsletter a year. The infrequency was due to a lack of volunteers to take on the task. There was serious consideration of the provision of a newsletter and lack of a frequent publication was seen by the leader as a deficit within the group.

The Fibromyalgia group published their newsletter seasonally and this frequency was only temporarily stopped after Claire's partner had been diagnosed with lung cancer and a stroke in the year prior to observation of the group.

In both the Arthritis and Fibromyalgia group newsletters the format was almost identical. There was an update on the group's activities, photographs from social gatherings as well as updates from group members who had been ill. However the Fibromyalgia group also reported on the lobbying activities of Claire and Jen, these included the campaign at the local rheumatology outpatients department. In addition Jen and Claire had attended a meeting with local politicians to campaign for separate fibromyalgia clinics. This campaign was spear headed by the Fibromyalgia Association and group members were encouraged to send members of parliament template letters which it was hoped would bring about much needed awareness of the illness.

Summary of Instrumental Support

The medically unexplained nature of fibromyalgia identified that communication with medical professionals was an important aspect of support group function by Claire. This is in response to her lived experience of contact with a medical professional who saw her illness as having more of an impact on her emotional health. There was evidence from the interview data of David that the focus on communication to medical professionals helped him to negotiate a lower dose of amitriptyline which impacted on his daily routine. However David reported that the focus of the consultations was often dominated by his co-morbid illness. Claire identified with the members of the group's circumstances when they attempted to focus on the symptoms of fibromyalgia. The comparison of people with fibromyalgia being like bargain shoppers helped to illustrate the frustration felt in the pursuit of a satisfactory outcome from a consultation. Claire also suggested that members of the group made lists of bothersome symptoms prior to a consultation as an aide memoir. The ideal solution for this group would be the provision of specialist fibromyalgia clinics within the National Health Service (NHS) staffed by empathetic and knowledgeable healthcare professionals as was often reported to be the case in the United States of America.

The Arthritis Group funded places for group members to attend the Challenging Arthritis course. Previous observations of this group were that meetings were attended by people in the present self of the chronic pain trajectory. This finding is important because of the cost implications as well as the disengagement and relatively high dropout rate reported in chapter two.

The identification of the three selves can make a contribution to further recognition of the ideal candidate. This group was the only one to offer self management programme.

The Arthritis group also appointed a Welfare Officer which is a response to the written constitution. The provision of welfare officer was reported as being a response to group members' needs in rural or isolated communities or in large cities such as London with a transitional population which may not have a natural support network in the vicinity. The MS group members chose to develop a less formal approach to ensuring contact with members who were unable to continue with their membership. The development of this outreach group had advantages for Alison who felt that it gave her a purpose and also helped to invest in the prevention of isolation should she be unable to continue to attend the meetings. The outreach programme also recognised that a member's isolation could have an impact on dependants of that person and addressed the issue by extending the scope.

The telephone helpline was used more by members of the fibromyalgia group and was initially operated on an open basis. The scope of the individual's health issues who used the service had an impact on the emotional health of Claire who decided to limit the hours the service was in operation. The MS and Arthritis groups' telephone helpline was not used by members seeking advice but as a point of contact to update the leader and as a consequence the group about progress following operations in the case of the Arthritis group and as a point of enquiry for the MS group.

The newsletter was abandoned by the MS group and the reason for this was the health of the leader as well as the weekly meetings offered by this group. The leader of the Arthritis group saw the lack of a regular newsletter as a deficit within the group. The group did publish a newsletter at least twice a year but the leader felt that this was inadequate but the lack of volunteers to take on the task maintained this status quo. Claire felt that the newsletter was a further method of outreach for isolated members. The newsletter was focused on updating members about local activities such as the meeting with medical consultants. The victory of having the Arthritis Care booklet regarding fibromyalgia removed in favour of the locally written information gave this group purpose. The continuing struggle to have fibromyalgia recognised within the health service was certainly a focus for the group as well as for the newsletter.

8.5 Summary of Social Support Findings

In this chapter the social support activities of the sampled groups was explored. The four elements of social support identified by Langford et al (1997) were discussed and presented in contrast to the reviewed support group literature in chapter three, where social and informational support were reported as separate entities.

The informational support offered by each of the groups was discussed. Prior to this the informational resources offered to the interview participants before support group membership were presented. The reason for this was that information seeking was identified as a motivational factor for membership in chapter seven.

There was also evidence provided by the observation and participation in the groups as well as the accounts of the interview participants that emotional support was provided by the sampled groups. The support needs of partners /carers who were welcomed at the Arthritis and Fibromyalgia group meetings were also discussed. In their accounts the interview participants also expressed the impact that their health circumstances had on those in their natural support network.

There were fewer examples of appraisal support in each of the support groups with the exception of the exercises in the MS group. This suggests that the purpose of support groups is strongest with only three elements of social support including information, emotional and instrumental.

The instrumental support offered by the sampled groups addressed the needs of a particular condition for example the need for effective communication with healthcare professionals was seen as a priority for those with a diagnosis of fibromyalgia. In the Arthritis group members were offered funded places on the Challenging Arthritis Programme and the positive response to this illustrated further the existence of the three selves within the chronic pain trajectory. The present self was apparent amongst the members of this group and the results of this are discussed in the contribution to existing knowledge on page 344.

The identification of the three selves within the chronic pain trajectory impacted on each of the elements of social support. This finding also contributes to the existing knowledge regarding support groups in that group planning and the targeting of advertising campaigns can benefit from this.

The impact of the three selves to healthcare professionals, patient associations, self management programmes and charitable organisations sponsoring support groups will be discussed further in the contribution to existing knowledge page 344.

8.6 Summary of Key Findings and Contribution to Existing Knowledge

The aim of this section of the chapter is to summarise the key findings of this current study and discuss their contribution to the existing body of knowledge. The key findings are identified as *group demographics, existence of core members, impact of layout of meeting rooms and the three selves of chronic pain*. Each of these findings is discussed in their respective sub-headings.

The group demographic findings of this study encompass the dominant gender of the sampled groups as well as factors that motivate an individual to join a support group. In this section the underrepresentation of people from diverse ethnic backgrounds will also be discussed.

The identification of the existence of a core group of members impacted on this study. The existence of the core membership had positive and negative consequences for the groups. Positively the core group involved themselves in a variety of the groups' activities, they were the main source of the interview participants, and they ensured the longevity of the group. Negatively the core group in the Arthritis group may give the impression of tribalism and therefore a closed group to new members.

The room layout of each of the groups was dictated by the format of the meetings for the MS and Fibromyalgia group. In the Arthritis group the room layout was dictated by the committee that ran the meeting hall, the primary purpose was to provide lunch for older adults in the daytime. The impact that the layout had in the Arthritis group was a further impression of the existence of tribalism.

The format of the meetings in the Fibromyalgia group had an impact on the scope to socialise and form links which may be of benefit for individualised emotional and informational support.

The experience of co-morbid illnesses was a source of frustration for those in the Fibromyalgia group because of their impact on medical consultations. The interview participants from all three groups experienced co-morbid illnesses and demonstrated that they were self managing these well. They did not identify themselves as patients of these illnesses but people experiencing them. The existence of the co-morbid illness and the discussions in the interview contributed to the recognition of the *three selves of chronic pain*.

The existence of the three selves of chronic pain was identified by elements from each of the key finding identified in this section of the chapter. The three elements of this include *the past self, the chronic pain self, and the present self*. The existence of the three selves also contributed to the motivation in joining the support group.

8.6.1 Group Demographics

The gender representation of the Arthritis and Fibromyalgia groups' demographics reflected the epidemiological work by Macfarlane et al (2001) and Breivik et al (2006) which reported that a high proportion of females reported chronic pain. The MS group had equal representation of both males and females but Alison was the only member of this group identified as experiencing chronic pain. The description of the purpose of this group differed according to gender with males referring to it as *going to the gym* and females as attending a *keep fit classes*.

This aspect of gender identification of group purpose was reported by the participants in the fitness exercise group in the study by Paulson (2005).

The motivational factors identified by the interview participants for joining the support groups included information seeking, increasing their social networks, health professional recommendations and starting the group. These factors have been reported in the reviewed support group literature in chapter three (figure 3.4, page 132).

Philanthropic reasons were also reported in this current study and this was not identified as a motivating factor in the literature (figure 3.4, page 132). Philanthropy was identified by Deidre and Brian but their motivations differed. Deidre wanted to help others in a similar situation to her own. Brian felt that he wanted to give something back to society after his numerous contacts with the formal healthcare system. The impact of joining a support group for philanthropic reasons for Brian was an active retirement, a contribution to his quality of life and a role within the group as a fundraising officer.

This current study reported that there was underrepresentation of people from differing ethnic backgrounds in all the sampled groups. The MS and Arthritis group were exclusively populated by white British or white Irish members. The Fibromyalgia group had members from an Asian, Black Caribbean and Somali background but these ethnic backgrounds were only represented by three people. The sampled groups' ethnicity did not reflect the diverse population of their locations. Claire was the only group leader that identified this as an issue and made attempts to reach out to a more diverse population. Although she recognised that the language barrier was a salient reason for people not joining a support group. She still maintained the importance of making people aware of the existence of the group. She advertised widely across the city.

Claire did report that people from different ethnic backgrounds used the group's helpline but this was a relatively small number. They used the helpline to talk to Claire about issues they had with their employment as well as litigation they were currently undertaking against employers. The evidence provided by Claire could suggest two things; firstly that ethnicity is a barrier to joining support groups. Evidence for this is provided in the use of the telephone helpline as opposed to group attendance, although there may also be issues with taking time off work to attend the group meetings. Secondly there could be a cultural explanation in that there is a lack of need of a group because support is available in an individual's natural network. Evidence for this is provided by the lack of response to the policy of prolific advertising in all areas of the city by the Fibromyalgia group.

In this current study Hilary was relatively newly diagnosed with fibromyalgia in comparison to the existing membership of the group she attended. In her interview she reported that she was motivated to join because of the recommendation of her general practitioner. In the studies by Cooper and Burnside (1996) and Hildingh and Fridlund (2001) it was reported that information about groups given by healthcare professionals resulted in a relatively high figure of participation. Hilary's account suggests that she joined the support group to appease her general practitioner and not because of a mutually agreed decision. There was a need to do this when she felt that he was a professional who had empathy. Hilary joining the group in this way was not successful and led to her eventual rejection of the group after attending four meetings. She believed that the group did not offer her anything of significance. Hilary's needs at the time of attendance were for her to understand the clinical characteristics of fibromyalgia and to discuss her personal circumstances

This would suggest that there was a misunderstanding of when group membership could benefit Hilary. The results of this study are that there needs to be recognition of the location of an individual within the chronic pain trajectory for them to take advantage of the support provided by groups. The identification of the *three selves* of chronic pain suggests that Hilary is currently experiencing the chronic pain self and as a consequence will not benefit from group membership as she remains in the healthcare system and is also clinically focused. The new members who attended one meeting but did not return to the meetings at the fibromyalgia group also suggest that there was a lack of understanding of the purpose of support groups by members of the public.

The effective use of funds for charitable organisations is a positive contribution that this current study has on targeting advertising to the relevant people. Those experiencing the *present self* appear to be the individuals that benefit the most from support group membership. The results of this study also show that the present self influences the type of information that is beneficial to an individual in their approaches to self management and coping.

8.6.2 Existence of Core Members

This study identified the existence of a core of members in each of the sampled groups. The existence of the core group has been identified in this current study as an important element. The core group are involved in numerous activities within and out of the group.

These include philanthropic activities such as supermarket and street collections and other fundraising activities which have been reported as contributing to quality of life through an active retirement and provision of a social role. The existence of the core group also helped to maintain the longevity of the group. Although the MS and Fibromyalgia groups disbanded during this current study they had been active for a number of years. The disbandment of the group was in response to the health of the leadership and not because of a lack of need. The groups may reform out of necessity and the new leader could be sourced from the core group members. Although in the observation of the sampled groups' core members did not come forward when the retirement of the leaders was announced.

The core group was also the source for the interview participants and their experience and understanding of the group partially contributed to the identification of the *three selves of chronic pain*. The core group members were also more likely to participate in the committee which provides further evidence that if there is a re-launch of the MS and Fibromyalgia groups, the source of a potential leader could come from the core members. In the Arthritis group the core members also helped the charitable organisation with their current campaigns, such as the active retirement focus group.

Members of the Arthritis core group were more likely to put themselves forward for the Challenging Arthritis programme. In chapter three, page 117 it was reported by Koch et al (2004) that the *self* was often missing from self management programmes.

Criticism was made that these programmes were *off the shelf* and *prescriptive* and both

Koch et al (2004) and Davidson et al (2005) recognised that the success of self

management programmes was not only dependent on self efficacy but also on other

psychological factors such as need for personal control. Analysis of the observational

data from the Arthritis Group suggests that individuals in the core were experiencing the

present self and this impacted on the likelihood of their intention to participate in the

Challenging Arthritis programme. They were also more likely to engage, as well as

share new found knowledge with others in the group. They also recognised that the

programme contributed to their existing knowledge. Mary reported that attendance at

the programme would help to contribute towards her long-term goal of an active

retirement because of the opportunity to become a lay leader on the course. Although

this was not the goal for Deidre, she reported that attending the programme helped

refresh her existing nursing knowledge as well as introducing her to new ideas and

skills.

In the MS group the core members also provided an informal outreach programme to

prevent isolation of group members who were experiencing difficulty in attending the

meetings.

8.6.3 Impact of Layout of Meeting Rooms

The layout of the meeting room impacted on a number of the findings in this current

study. The members of the Fibromyalgia group were less likely to sit in the same places

at each of the meetings and although this gave the perception of an *open* group for new

members it also had an impact in the formation of smaller groups which evidence from

the Arthritis group, where people grouped together, suggests are a further source of

informational and emotional support. The format of the meetings at the Fibromyalgia group represented a classroom orientated meeting, in that members attended to learn more about their condition. The guest speakers who were invited to talk at the meetings were health focused. The absence of healthcare professionals willing to talk at the group was related to the choice of alternative therapists as speakers. Some members of this group found that the guest speakers were irrelevant to their circumstances because many found that the prices charged were prohibitive for those on a strict budget. This is in contrast to the format of the Arthritis group where people attended to socialise and guest speakers who inspired members to take up new hobbies and interests were viewed positively. In addition guest speakers who inspired through overcoming adversity such as the sight impaired individual who was invited to speak about using a guide dog were also popular. There was an observation made that the set up of the meeting room for the Arthritis group had the tendency for members to gravitate to the same places at each of the meetings. Although Mary suggested that this was not coincidental and people experiencing similar arthritic conditions sat together to share emotional and informational support. However the impact of this *grouping* of members excluded others and could give the impression of tribalism and therefore a closed group. Evidence for this was provided by Mary who felt at times that being the only individual with psoriatic arthritis excluded her.

The exercise component of the MS group reflected the room layout this group's meetings which was also the reason why guest speakers as well as partners/carers were not invited.

8.6.4 Co-morbid Illnesses

This current study also reported the issues of co-morbid illnesses which were experienced by the majority of the interview participants. The accounts of the interview participants from the Fibromyalgia group identified that co-morbid illnesses were managed well and there was a general feeling of frustration that medical consultations did not focus on the fibromyalgia which for many was felt to require more attention and support. The identification of the existence and affective management of the co-morbid illnesses also contributed to the identification of the *three selves of chronic pain*. The reviewed support group literature (figure 3.4, page 132) did not report the presence of co-morbid illnesses. This impacted on the selection of groups to be a member of with the primary illness identified as dominant in help seeking.

8.6.5 The Three Selves of Chronic Pain

The *three selves of chronic pain* was an important finding in this current study and contribute to the existing knowledge about support groups. In the study by Subramaniam et al (1999) the reason for participation in the group was given as an individual's adaptable approach to managing their pain. However the Subramaniam et al (1999) study was not able to provide a location in the chronic pain trajectory of when this motivation may be strongest. The consequence of identifying three distinct phases within this trajectory helps to understand this further. The three phases are identified as; *the past self, the chronic pain self and the present self*.

The *past self* had contrasting characteristics which were dependent on the illness diagnosis as well as the individual. Alison reported that her past self was an idealised family unit that did not need anybody from the outside to help it to function. The

members of the Arthritis group measured their past self in terms of work ethic and work based efficiency and the people they were. The unexplained nature of fibromyalgia resulted in the past self as a source of pinpointing events which may provide answers to the presence of the illness.

The *chronic pain self* is less contrasting across the groups in that individuals' become clinically focused and are likely to experience similar attitudes to death and dying identified in the work by Kübler-Ross (1969). More recent work by Walker et al (1999) identified a theme entitled '*they do not understand*' in their study of individuals with chronic pain who are exposed to the healthcare system, which is also deemed to promote passivity and powerlessness. In the *chronic pain self* there is also a sense of the *self disrupted* which is combined with losses and fears identified in a study of individuals who have undergone a coronary artery bypass graft by Leegard and Fagermoen (2008). The experience of those with fibromyalgia suggests that the *chronic pain self* is further compounded by the lengthiness of achieving diagnosis. The results of this current study suggest that those located in the *chronic pain self* aspect of the trajectory would not benefit from membership of a support group. The reason for this is that there is still a hope for a cure and they remain within the system which gives their health a clinical focus compared to those who are experiencing the *present self*. The Fibromyalgia group helped to provide evidence for this, there were a number of new members who attended only one meeting. These individuals wanted to see others who were experiencing the illness and they did not return to the meetings. There is a risk that exposure to people who are seen to be coping, for instance experiencing the *present self*, could be potentially devastating for those in the *chronic pain self*. The reason for this is located in the continued hope that a cure can be found in the *chronic pain self* and

seeing others who have been experiencing the condition for years may nurture hopelessness and may delay the transition between *the selves*. Although those in the *present self* may offer inspiration in medically unexplained illnesses such as fibromyalgia but the meeting format is not conducive to this. Hilary's account and rejection of the usefulness of the support group at her particular location provides the evidence for this.

The *present self* in the chronic pain trajectory is the location where membership of a group can reap the most benefits for the individual. There is a sense of acceptance which has been identified in the work by Kübler-Ross (1969). Applying this to the context of chronic pain Walker et al (1999) report a theme of '*coming to terms*' and Vianne et al (2003) identifies two components of acceptance of chronic pain. These include a capturing of normal life despite the pain and recognition that a cure is unlikely and to search for one only avoids engagement of normal life. The *present self* allows individuals to explore self management techniques and in the Arthritis group nurture engagement with the Challenging Arthritis programme.

The *three selves of chronic pain* also impacted on the social support activities of the sampled groups. Social support has been identified by Langford et al (1997) as consisting of four components; *informational, emotional, appraisal* and *instrumental*. In this current study observations were made of evidence of these four components, whereas in the reviewed support group literature in chapter three informational and social support activities of groups were reported as separate entities.

Information seeking was identified as a motivational factor for joining a support group.

The interview participants were asked about the information they were given in the National Health Service prior to their group membership. This information was described by many as inadequate, Brian and Janet and seen the progression of information provision in the NHS from too little at the beginning of Brian's trajectory to too much at the present time. Those in the Fibromyalgia group were dissatisfied with the information authored by Arthritis Care. The results of this were that information produced by the group was gradually replacing the Arthritis Care information and prior to this, on a national scale, led to formation of the Fibromyalgia Association. The provision of quality information written with the inclusion of or by those experiencing the illness is a requirement of the information standard (DoH, 2009).

There was evidence to suggest that the *present self* impacted on the informational needs of those in the Arthritis group. Factual information was rejected in favour of real life information which was provided in the magazine *Arthritis News*. The reason for this was that members of this group were generally looking for inspiration.

In addition the length of time that many in the group had been diagnosed and there was recognition that nothing new was emerging from the NHS. This provides further evidence of the existence of the *three selves* in that Walker et al (1999) and Vianne et al (2003) recognised a frustration with the system and there is an acceptance that no cure will be found. In contrast the factual information provided by the Fibromyalgia group was very popular but this does not suggest that those in this group are still experiencing the *chronic pain self*. The medically unexplained nature of this illness results in the need to be aware of emerging information which is contrasting to the lack of new information for people with arthritis or multiple sclerosis.

The lack of chronic pain discussions within the groups is justified because of the *present self* location of the members of each of the groups. In the MS group Alison was the only member who identified herself as experiencing chronic, this combined with the exercise focus and the socialisation within this group meant that group discussions were light and often featured television programmes as the main theme. In the Arthritis group Mary suggested the chronic pain discussion occurred within the smaller groups. In the Fibromyalgia group personal discussions were discouraged due to the limited time of the meetings. In addition the members chose not gravitate to the same group of people at each meeting and this resulted in the lack of social networking which Hilary believes would have benefitted her.

**An Ethnographic Study of Support groups; the Pain Accounts of Older
Members
(Volume 2)**

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Chapter 9 – Discussions and Study Limitations

This current study focused on the purpose of support groups from the perspective of older adults with chronic pain. This chapter will discuss aspects of the method used and also report on the limitations of this study. The discussions are presented as subheadings each referring to the research areas where potential issues arose and how they were addressed. This chapter will also reflect on my development as a researcher. The chapter is partially inspired from the field notes I made during the observation phase and memos and notes I made after the interviews and during in the data analysis.

9.1 Study Limitations

In chapter three (page 106) Dibb and Yardley (2006) reported that there were two website data bases that provide information of over 2000 illness support groups in the United Kingdom. In contrast Munn-Giddings and McVicar (2006) reported that no such data base existed. Locating these databases for the current study was not achieved.

The sampled groups for this current study were not chronic pain focused. Chronic pain groups were located and approached but the meeting format did not comply with the operational definition of the support groups identified in chapter four on page 171. One of the groups, Pain Association Scotland responded by informative letter which explained that they had no problems with my research proposal. They further explained that they did not run support groups but staff led self-management groups. There was also a discussion regarding the classification of older adults as the majority of people who accessed their service tended to be in their mid 30s to mid 50s.

The group was not included in the study because of the small representation of the studied age cohort. Additionally the group was also based around self-management rather than a lay lead support group. This was similar to the response received from the Coping Group. The group was administered by psychologists. Participants of the group would attend the meetings for a set period to learn self management techniques. The administrator of the group also explained that because of the dynamic of the group I would only be able to attend two meetings. There was no response from either Action on Pain or the Endometriosis groups. If the groups I had sampled were chronic pain support groups the finding may have reflected the needs identified by the participants' of the Subramaniam et al (1999) study. These include an enhancement of the telephone support network, an increase in access to informational resources on pain and pain management, more social outings and a higher public profile of the group. The impact to this current study of not having support groups that were chronic pain specific I reported in chapter eight, page 304 regarding discussions of chronic pain which were contrasting across the sampled groups. The MS group did not discuss pain but multiple sclerosis was also not discussed in depth, this reflected the social element that was prevalent in this particular group. The Arthritis group members continually rejected inviting speakers who would discuss treatment and management of this painful condition. However there was an opportunity to attend the Challenging Arthritis course, which addresses the self management. The Fibromyalgia group discouraged discussions of personal illness accounts due to time restraints but did invite speaker who discussed trigger points. However participation in the sampled groups did include contrasting degrees of the four components of social support identified by Langford et al (1997).

There were issues of the approach I took in capturing group consent (page 357). During my observation of the Arthritis group there was one incident that made me aware that consent had not been obtained. In chapter six page 237, I discussed the layout of the room and how in this group people tended to gravitate to tables of four. I approached one of the tables this resulted in a stoppage of their conversation. I therefore did not report the conversation and moved away as I believed that these individuals were not consenting to be studied. This was the only reportable incident that I came across during my participation of all three of the sampled groups.

In the MS group only one potential participant was identified by the group leader. She introduced me and I discussed the study further and gave her the written information. The issue with this group was that I was not offered the opportunity to discuss the study with the group as a whole. There were perhaps elements of protection of members by the group leader or miss communication of the aims of the study. The outcome of this was that I only interviewed one group participant.

A female Fibromyalgia group member was angry that she would be excluded on the grounds that she was not old enough to participate. This resulted in further explanations of current government policies and under representation of the older age cohort within the literature. I felt that it was important to highlight increasing interest by central government in self management activities of people experiencing long term conditions and that I had chosen to focus on older adults.

9.2 Research Role

I had recognised the potential problems of the role of the researcher from the ethnographic literature. There were however a number of assumptions I made. The primary assumption was that approaching the groups as a nurse researcher would permit me unquestionable access to the groups. I identified myself as a registered nurse during the introductory telephone conversations with the sampled groups' leadership. I also identified myself as a nurse during the explanation of the study to the Arthritis and Fibromyalgia groups. My choice to approach the groups as a healthcare professional may have had a negative impact on the recruitment of interview participants from the Arthritis group. The group is comparable in size to that of the Fibromyalgia group. I observed the Arthritis group for the longest period but only interviewed three participants. The possible explanation for this is found in subsequent observations of this group. Firstly, they had rejected guest speakers who would discuss elements of arthritis as an illness. Secondly they favoured speakers who inspire through discussions of hobbies and interests. I was not aware of this until I had observed the group for around three meetings. If I was to approach this group again I would have asked to speak to them after I had observed them for a number of meetings. I would briefly mention my nursing background but focus more on what I had observed subsequently. In contrast the Fibromyalgia group were aware of my professional background but this was not seen as a deterrent for volunteering. I sourced the majority of the interview participants from here. I cannot report whether my professional background or the opportunity to share their particular accounts influenced their motivation to participate. Following a review of his transcript, David informed me that he hoped that his account would help others with fibromyalgia.

I can also report that opinions about an individual's particular medical care were never sought from any member of any of the sampled groups.

Approaching a group as a healthcare professional has other issues. My nursing background could have created a professional patient relationship with those I had come to know. This could have impacted on the equal relationship I had set out to achieve through the potentials of dependency. However I did not come across any ethical dilemmas and none of the participants of the study asked me for advice. In the Fibromyalgia and Arthritis groups Hilary and Deidre were retired nurses and this may have helped prevent advice seeking by participants. Although David (Fibromyalgia group) and his partner did speak to me some weeks after his interview about a consultation he had relating to his fibromyalgia. He was not however seeking advice but was expressing concerns about the focus of the consultation being on his secondary illness.

In the reviewed support group literature (Chapter 3) I was also made aware of the potential impact that approaching a support group from a nurse's perspective may have. Cooper and Burnside (1996) and Marzen-Groller and Bartman (2005) established their support groups from a nursing perspective. The results were that healthcare professionals and potential group members have differing interpretations of the purpose of the group. The interpretation of what makes a good group for a potential group member is rooted in the subjective nature of the illness experience and their needs as a consequence of this. This was reflected in the members of both groups formed by Cooper and Burnside (1996) and Marzen-Groller and Bartman (2005) rejecting the educational elements of the group.

This particular aspect was assumed to be a need and an important element of the group by the nurse researchers. Marzen-Groller and Bartman (2005) acknowledged that their approach was problematic and corrected it. They report that by correcting their approach the support group began to thrive and attract new membership.

9.2.1 The Group Leaders' Interpretation of my role within the Groups

What was not envisaged in this current study was that role identification by the researcher is only part of the consideration. The group leaders had additional interpretation of my role and this was dependent on the group. The Arthritis Group leader insisted that I became a full member of Arthritis Care which resulted in the payment of a yearly subscription to the NCO as well as local subscriptions and beverage charges, payable at each meeting. The fibromyalgia and MS groups had policies in place which exempted guests from subscription and beverage charges.

None of the three group leaders viewed me as a healthcare professional advisor for their groups. The leader of the Arthritis Care group, who was philanthropic, saw my university background as an opportunity to raise funds. I addressed the question of raising funds through an explanation that as a PhD student I was not exposed to a large cohort of students. Neither, as he suggested, would I be prepared to walk from public house to public house shaking donation buckets in drinkers' faces. I did, however, participate with fundraising by donating three redundant mobile telephones to the group's recycling scheme and sold two books of raffle tickets. In contrast the leader of the Fibromyalgia Group looked upon my nursing background as a group asset. I was introduced as a nurse from the university to invited guest speakers.

9.3 Locating Support Groups

Disappointed with the initial internet search I conducted another search after visiting local primary and secondary care locations the results of which provided me with *specific* website addresses and indicated that I needed to refine the keywords. This refining included using the actual medicalised terms e.g. arthritis, fibromyalgia. This resulted in more specific local groups as well as national charitable organisations which offered online support forums.

A member of staff from a pain clinic informed me that there had previously been support groups. These were established by participants of the pain management course but this was no longer the case. They suggested that people were more likely to meet informally in public places such as the local shopping centre, which were also the findings of the study by Cheang (2002). This impacts on the accuracy of how many groups there are in the United Kingdom but is more reflective of the spontaneous and anti-bureaucratic groups described in the study by Adamsen and Rasmussen (2001)

9.4 The Sampled Groups

9.4.1 The Research Communities Relationship with Support Groups

The leader of the Fibromyalgia group made numerous enquiries about the study. She informed me that she was not happy to allow access to her group for questionnaires because the group had previous experiences of students surveying the members and not sharing the results. The initial impressions I formed about this group were one of a collective disillusionment with the research community.

To overcome this I chose an approach that would update the sampled group's frequently about the progress of this current study. This approach also benefited the reliability and rigour issues of this study. Periodic feedback of my work made it less secretive and helped fulfil the intended feminist leanings of the study.

In the experience I had of the support group for parents of preterm or sick neonates I described a progression of support. This aspect of the neonatal support group was an important difference with the groups that were sampled in this current study. The support offered by the preterm or sick neonate group was excellent in supporting parents' but addresses the immediate needs of having a baby on a unit that many had not been aware of prior to the birth and subsequent admission. Many of these babies were discharged with complex needs and many parents turned to further support groups which focused on their particular unique circumstances. This is in contrast to members of the groups sampled in this current study.

Members were informed of the findings relating to routes to joining and although the findings were similar to other studies of support groups e.g. informational support, seeing others in similar circumstances. They also felt empowered when they realised that there were also philanthropic reasons for joining the group. This was viewed as positive by many of the members of the sampled groups because it recognised positive aspects of their current circumstances and confirmed a social role as well as their ability to give something back.

9.4.2 Security of Group Members

The Fibromyalgia group leader also informed me that security of her group members was priority. She required for me to bring my University identification, ethics approval, the study protocol and contact details of my supervisory team. This group was the only one in the sample that requested this information.

9.4.3 Language Used in Groups

The language used when presenting the study to the sampled groups needed careful consideration so that I did not isolate or offend the intended age cohort. When discussing the age cohort for the interview accounts. The term older adult was substituted for the term people over the age of fifty five.

9.4.4 Sampled Groups Characteristics

Each of the sampled groups differed in their characteristic which has been identified in a study by McDermott (2005). This is identified as the most striking characteristic of all groups (McDermott, 2005). The results of this are that support groups are difficult to research because of their incomparability (McDermott 2005). I addressed this issue by reporting distinct characteristics and the commonality amongst the sampled groups.

The characteristics of the sampled groups are discussed further in chapter eleven, page 380.

9.5 Obtaining Group Consent

In the beginning of the observation period I was invited to present my study by the leaders of the Arthritis and Fibromyalgia groups, this was negotiated before I started at the group.

This approach formed part of the informed consent process, in that verbal information was given to the group members and written information was given to potential interview participants. This approach also gave people the opportunity to ask me questions about the study before making the decision to participate in either the observations or interviews.

There is little written about capturing group consent in the literature. However Dench et al, (2004) addressed some of the issues of whether group consent should be written or verbal. To overcome the paucity in the literature regarding group consent, the issue was discussed with each of the sampled group leaders on first contact and prior to my first meeting. It was agreed by all of the leaders that my presence and purpose at the meeting would be made clear to all of the members. Dench et al (2004) suggest that there is an increasing tendency for ethnographers to obtain consent at the end of the period of observation. In this current study group consent was an ongoing process because of the flexibility of attendance at the meetings. I also obtained verbal consent at the end of the period of observation but this was only possible for the Arthritis group due to the closure of the MS and Fibromyalgia groups. Group consent was captured verbally.

In the MS group I was left to my own devices regarding informing members about the study and also asked individuals if they had any objections. The group leaders of the Arthritis and Fibromyalgia group felt that not all members would feel comfortable expressing their objections in the group setting. The solution was that individuals with an objection would be able to express their concerns during break periods or after the meeting.

During the study presentation to the Arthritis and Fibromyalgia groups, I emphasised the voluntary nature of participation and the individuals' right to refuse. Group members would also be reassured that their refusal to participate would not affect their membership or role within the group.

9.6 Interview Participant Sampling

The study by Cooper and Burnside (1996) suggested that people may only attended one or two of the group meetings, Elsdon et al (2000) estimated that only fifteen members actively attend meetings and the study by Subramaniam et al (1999) reported that the mean age in their group was fifty three years. These factors gave me a realistic idea about the number of older adult participants that may volunteer for the interviews. The interview participants were identified differently across the three sampled groups. I presented my study in the first three meetings of the Arthritis group and this resulted in a slower recruitment but a chance for me to establish myself in the group and become a known face. The participants in this group were interviewed two months apart but there was an unexpected advantage to this in that I was able to establish rapport within the group. In contrast the Fibromyalgia group leader asked for people who were interested to put their names and contact telephone numbers on a sheet of paper at the end of my presentation. This resulted in six volunteers including the group leader and I spoke to them further after the group meeting and handed them the information sheet for the interviews. I then agreed to contact them by telephone at a prearranged time. One of the initial volunteers informed me that she had changed her mind after speaking to her partner and the exacerbation of her pain which had an impact on lowering her mood. She did not attend another group meeting during my participation.

The remaining volunteers were approached at the prearranged time and dates were made for the interviews. The interview dates were often between meetings and away from the group to allow participants to talk freely in their own environment, around half of the appointments needed to be rescheduled due to illness or chronic pain flair ups.

Logically I felt that by establishing myself in the group first I could gain some insight and knowledge about the group which would be important prior to the semi-structured interviews. It was also seen as an important approach in engaging potential interview participants who would have the opportunity to put a name to a face and ask further questions about the study. This approach is reported by feminist ethnographer Sherman Heyl (2001) as helping to establish respectful ongoing relationships with participants. The timings of the interviews were in contrast to the study by Subramanian et al (1999) who conducted their interviews as soon as possible after the individual contacted the support group.

Recruitment for the interview stage of this current study was voluntary. The groups approached this aspect in very different ways. The interviews were conducted in the participants' homes but provision was made to conduct the interviews at a room in the university. The support group meeting rooms were also considered but the three group leaders said that the room was occupied after their meetings by another group. The interview participants remarked on the convenience of being interviewed at home. Two of the participants from the arthritis care group invited me for an evening meal which gave a social emphasis to the interview process as well as further confirmation of my establishment within this group.

The Arthritis Care group were informed about the study and then asked to consider volunteering for the semi-structured interview. After three presentations of the study and a further two meetings where I didn't present, I was approached by three potential interview participants who were given written information. However, the first interview with a member of the Arthritis group but this took place after I had observed the group for five meetings. The participant had been hospitalised for elective surgery to their shoulder. The participant also opted to be interviewed with his wife. This influenced my decision to offer the option to potential participants to be interviewed with their intimate peers/carers. Information sheets and Consent Forms for intimate peers/carers were developed and approved by the FREC. The length of each interview varied from one hour to two hours. Nine older adult support group members were interviewed and recruitment was stopped because no further participants volunteered. The interview participants across all the sampled groups attended most or all of the meetings which suggested that there was a *core membership* within the groups.

In chapter five, page 217 I discussed the interview schedule but in reality this was only referred to minimally. This is because of the length of time I spent in the groups which resulted in a natural rapport with the participants. My feminist sensibilities which were highlighted in chapter five, page 200 helped to prevent objectifying the study participants, this also impacted on analysis of the data. Many feminists relinquish to some degree control of the research such as analysis and outcome (Skeggs, 2001). Further if the researched do not like the explanations given they should have the right to prevent publication (Skeggs, 2001). This approach to the current study sits comfortably with the group consent procedure reported earlier on page 211.

9.7 Negotiating Departure

Negotiation regarding departure from the sampled groups began at initial contact. The leaders of the groups were informed of the intended length of time I wished to observe the groups. The plan was to alert the leaders and the group members that I was leaving at least two meetings prior to my eventual exit. There was also the need for me to reassure the groups that I would return to discuss the final study outcome and also to remove any data that the groups felt would not be helpful.

In reality the MS and Fibromyalgia groups disbanded before the departure plan could be implemented. This impacted on the dissemination of the results which is discussed further in chapter ten, page 370. The decision to exit the field was only relevant to the Arthritis Care group. Discussion of exiting this group began two months (two meetings) prior to my eventual departure. On reflection the amount of time I had spent with this group gave me a sense of belonging and I found it difficult not to return. Towards the end of the long observation period I became aware that I was looked upon as an extra pair of hands by the group leader.

During my last meeting with the group I was asked if I would take on the editing responsibilities of the group's newsletter. I unfortunately had to decline as I would no longer be involved in the group. I maintained contact with the group leader of the Arthritis group via e-mail and this helped me negotiate my return to the group to feedback the findings of the study. I managed to depart without ill feeling and this is reflected in the number of Christmas cards I continue to get from the interview participants.

Maintaining contact with the leaders of the Fibromyalgia MS group was more challenging as the group contact telephone number had been disconnected so I corresponded via letter with little response. The limited response was due to the retirement of these two leaders and perhaps a removal from their involvement in the running of these groups.

9.9 Generalisability

The generalisability of the findings of this current study was based around who would be evaluating the findings. Initially I felt that the findings would remain within the group and charitable organisations that sponsored them, the findings would benefit the sampled groups in developing their understanding of the group from the perspective of older adults and what I had observed as a participant. This I felt would benefit formation and development of groups in areas that were devoid of such resources. The findings I also felt would benefit smaller local groups that were not affiliated to a charitable organisation. The generalisability of the findings could also contribute to the continued recruitment and sustainability of the group by giving an insight into why people where there and what they perceived the benefits of membership were. There also emerged a further group that could benefit from hearing the study, national patient networks such as *Involve* or the *Patients Association*.

9.10 Data Protection and Management

Participants were given the opportunity to remove anything from the transcripts that they did not feel comfortable with. In reality none of the participants felt that this was needed.

There is no standard operating procedure at the Sheffield Hallam University regarding the time period in which data must be kept. The pharmaceutical industry suggests that data should be kept for at least 15 years (when the patent of a compound expires) but I am not testing a compound. Discussion with the universities ethics committee resulted in the suggestion that the data should be safely stored for at least 10 years.

9.11 Reflection on Learning

The participant observation approach of the study I have recognised was a developmental stage for me as a researcher. Despite the development of the observation checklist in the initial group meetings I observed the familiar such as the demographics of the group including the age cohort, ethnicity and gender of members as well as foot fall, observing the familiar in the initial stages of ethnography has been identified in other nursing ethnographic studies by Murphy (2005). The field notes I made after each meeting identified that this form of observation was used in all of the groups during the first two meetings. This I felt isolated me and gave me the realisation that the observational data required more of a co-production between the group members and me. The approach of the participant observation changed as I began to develop and build relationships within the group and this helped me identify potential interview participants as well as develop my understanding of the sampled groups by talking through ideas and thoughts with others.

This current study has had various influences on my professional learning. The ease in which I integrated into the groups was reflected in many ways. The Arthritis and Fibromyalgia groups were examples of how I was seen as a group member when I was asked if I would edit the group's newsletter.

In the MS group integration was achieved by participation in the range of exercises at each of the meetings. Additionally the Fibromyalgia group leader often called me to discuss issues she was having with the day to day running of the group. In both the Arthritis and Fibromyalgia groups I introduced the leaders to potentially beneficial contacts. In the case of the Arthritis group this included the student disability officer who provided advice on advertising the group to students who were diagnosed with arthritis. This integration was more to do with my open and friendly approach as opposed to my nursing background.

The chosen qualitative methodology has been a departure from previous quantitative based studies which I managed on behalf of the pharmaceutical industry. The results of this are that I can see that there are benefits to both approaches as well as an ability to assert that neither should be viewed as more scientific or better than the other. I do recognise that each methodological approach is more appropriate to certain social research situations than perhaps others. Since completing this study I have rejected returning to the pharmaceutical industry and I am pursuing a career in academia.

Chapter 10 – Broadcasting the Results

The initial dissemination was conducted at three annual conferences; firstly the presentation was made at the Aberdeen Pain Group (Primary Care Pain Group, 2007) annual meeting, secondly at the annual conference of the Welsh Pain Society (British Pain Society, 2008) and thirdly at the British Pain Society's annual meeting (British Pain Society, 2010).

Disseminating the results to the sampled groups was less straightforward. The MS and Fibromyalgia groups closed down before the final results were available for dissemination to members as a whole. Presenting the findings to the whole of the Arthritis group challenged maintaining confidentiality of the participants from this group. In the initial conversation I had with Claire, the leader of the Fibromyalgia group, it was clear that she expected feedback of the results to the whole group. This, she explained was because in the past other researchers had sent questionnaires to the group but had never returned to share the results. This has highlighted the importance of dissemination to those who have been kind enough to share their accounts, as well as for the group members who shared conversations with me in the observation of their group. Claire described that the *hit and run* approach of previous researchers did not create a positive relationship between the group and academia. I had also identified in an early stage that the relationship between the university and the sampled groups needed to be preserved in case of further research. This chapter will report how I overcame these issues as well as discuss the broadcasting of the findings in more academic settings.

10.1 Broadcasting the Results – An Ongoing Process

The positive outcome of interviewing at an early stage resulted in discussions of the findings with the participants during the continued observations of the sampled groups. This permitted discussions about the data as well as seeking clarity and confirmation regarding my interpretations. The results of which were authenticated data as well as informed participants. In this way the broadcasting of the results was an ongoing process. This had the unseen advantage of not needing to develop an emergency contingency when I became aware of the MS and Fibromyalgia group closure. I will discuss on page 370 of this chapter, the closure of the MS group earlier than the others and the implications for discussions with participants from this group.

10.2 Broadcasting the Results in Academic Settings

In addition to broadcasting the results to the interview participants and the sampled groups, I was also invited to present at three annual meetings of the Aberdeen Pain Group Annual meeting (Primary Care Pain Group, 2007), the Welsh Pain Society (British Pain Society, 2008) and the British Pan Society (British Pain Society, 2010). The invitation to speak at these meetings was organised by my supervisor. The stage of the analysis of the data reflected the content of the focus of the presentation. The first presentation, at the Aberdeen Pain Group's annual meeting (Primary Care Pain Group, 2007) was conducted in the early stages of data analysis in 2007. The second presentation at the Welsh Pain Society's annual meeting (British Pain Society, 2008) was conducted one year later. The presentation at the British Pain Society's annual scientific meeting (British Pain Society, 2010) was in 2010 when the data was collected and analysed.

Prior to the meeting of the Aberdeen Pain Group's annual meeting (Primary Care Pain Group, 2007) I had interviewed and transcribed all of the participants' accounts. At this stage the focus of my analysis was the motivational factors that inspired the participants to become group members. The presentation (appendix 5, page 413) was focused on these reasons which were an adjunct to the final findings of the study. The sampled groups were inspirational in writing the presentation from this stance. The MS group at this stage had closed. There was also concern from the Charitable Organisation that supported the Arthritis group about the underrepresentation of younger members. It was important to highlight why people would join the group as well as their support needs. There was positive feedback after the presentation. This was measured by the number of questions that were asked as well as people talking to me after the meeting.

The presentation to the Welsh Pain Society's annual meeting (British Pain Society, 2008), (Appendix 6, page 418) was held when themes were beginning to emerge from the data. Although at this stage the categories for the data were still being refined. Therefore following a conversation with my supervisor the decision was made to present the decisions of the participants to join a support group. The reason for this was that I had previous experience of the presentation and also was aware of the type of feedback it had received. The earlier presentation (Appendix 5, page 413) was therefore refined with the addition of newly emerged data. In addition the questions and feedback I had received in the Aberdeen Pain Group (Primary Care Pain Group, 2007) meeting was also added. Interest following the presentation came from healthcare professionals who were interested in establishing chronic pain support groups.

There was also a discussion with three psychologists, one of whom felt that support groups offered more than the Expert Patient Programme (EPP). He felt the EPP would not benefit all people because of the differing speeds of learning and the shortness of attending meetings. He suggested that the results of further studies after this current study may yield a framework for helping to establish a successful support group. This will be discussed further in chapter twelve.

The third presentation was made at the annual scientific meeting of the British Pain Society (British Pain Society, 2010). This presentation was robust because the data had been collected and was analysed and the thesis was being corrected and finalised. The presentation (Appendix 7, page 429) focused on older adults and chronic pain and the advantages of support group membership. Following this presentation I was approached by a representative of the charity for people with trigeminal neuralgia who asked if I would be willing to work further with them to promote the work of support groups to potential members and healthcare professionals. This is discussed in further research chapter twelve.

The result of presenting in these settings was that I gained in confidence and reflected that this study was *heading* in the right direction. Presenting in this way was very inspirational and the discussions after my presentations helped to shape directions that I had not previously thought about. The impact of broadcasting the results at annual pain conferences has helped develop ideas for future research, which will be discussed in chapter twelve.

10.3 Arthritis Care

The results of the study were presented to the group one year after participation and negotiated my exit. An e-mail relationship had been maintained with the group leader. This made it easier in selecting a suitable meeting to present and discuss the results. The leader felt that it was important that the maximum number of people would be attending the meeting. The frequent e-mails at the time were intended to narrow down dates so that plenty of notice would be given to the group. I informed him that I felt it would not be beneficial to attend a meeting in the winter months due to the decrease in attendance. He and I also felt that it was important the interview participants were present.

The presentation I gave to the group was spontaneous and lasted around ten minutes with five minutes for questions. I also gave group members the opportunity to ask questions during the refreshment break as well as at the end of the meeting.

10.4 Challenges to Broadcasting the Results – Group Closure

Although I feel that the interview participants were informed of the results of the study I still obtained closure by writing a final letter to each of them. The letter illustrated the provision of social support that were offered by the groups. How this provision helped in some way to the contribution of their needs. There was also a hope that by illustrating the positives of the sampled support groups some of the former members may feel inspired to contemplate re-launching the group.

10.4.1 MS Group

The closure of the MS group occurred in the early stages of the observation phase. The results of this were that contact with the majority of the group members was severed. I

did have contact details for the group leader and her partner. The telephone number that I had been given in the initial contact with this group had been discontinued. I therefore contacted the group leader by letter expressing my sadness that the group had closed and wishing her luck with her retirement. I enclosed several copies of a brief synopsis of the study. The synopsis focused on the informational and support activities of the group. I asked if it was possible to for her to pass on copies to the group members that she was still in contact with. I did not get a reply from the group leader but I did receive a Christmas card which wished me luck with my studies and also acknowledged receiving the synopsis.

Alison was the only group member I had interviewed from this group. I spoke to her by telephone and asked her if she was happy to receive a synopsis from me. She agreed and I included contact details so that she could contact me if she had any issues with what had been said. Alison was the only interview participants with whom I had not had the opportunity to discuss in detail the findings and the ongoing analysis due to the closure of the group. I also received a Christmas card from Alison and she acknowledged receiving the findings synopsis.

10.4.2 Fibromyalgia Group

As I have previously reported discussion with Claire highlighted the importance of dissemination to the group. The group had expressed interest in this current study during my participation. They also expressed genuine interest in the study outcome. A possible explanation for this is found in the fibromyalgia written material that a number of the members choose to read. There was popularity within this group of text books that were intended for healthcare professionals. The group's library had

numerous copies of one book and it proved very popular. This, I have reflected several times in my field notes could affect how I present this current study findings to the group. Additionally I have also commented on a female member expressing her wish that speakers invited to talk to the group would speak in plain English. These aspects challenged affective dissemination. However the closure of the group resulted in a dissemination presentation not being possible. I therefore informed the interview participants of the outcome of the study via letter and a concise summary of the findings. I also wrote to Claire and asked her to pass on the study summary to group members with whom she was still in contact. I received a call from Claire some days later to inform me that she had passed on the study summary to the majority of the group members.

10.5 Broadcasting the Results Further Afield

The findings of this study, particularly the individuals' location in their chronic pain trajectory, may also benefit those who intended to start a support group. The focus on the chronic pain trajectory could help to target potential group members affectively. In addition the study findings could also be of use to national patient networks such as INVOLVE or the Patients Association. INVOLVE is a national advisory group in the United Kingdom which supports greater public involvement in the National Health Service (NHS), public health and social research. The organisation is funded by the National Institute for Health Research (NIHR). INVOLVE works with others towards the creation of the research community of the future which will be broader, more inclusive and more representative of the populations as whole (INVOLVE, 2010).

INVOLVE believe that members of the public bring perspectives and skills that are not always the same as those of researchers and health and social care professionals. Their involvement helps to ensure that the entire research process is focused on what is important to people and is therefore more relevant and acceptable to the users of services.

In contrast the Patients Association is a national healthcare charity which was established to campaign to improve patient services by listening to individuals (Patients Association, 2010). The charity also provides information and advice and helps individuals to get the best out of healthcare. The association gives patients the opportunity to talk about their experiences good or bad. They also conduct surveys on different aspects of healthcare intending to improve health services.

The philosophy behind these two organisation fits with the partial feminist stance of this current research. It was always intended that I did not conduct this study with an authoritarian voice and my interpretations of the findings would be discussed with the support groups. The findings of this current study would be of interest to both these organisations.

Chapter 11 – Conclusions

The aim of this chapter is to report the conclusions of this ethnographic study. However the nature of qualitative research does not aim to produce findings that are generalisable to a wider population. This study was conducted to investigate the purpose of support groups from the perspective of older adult support group members experiencing pain. Figure 11.1 helps to illustrate the overall findings and is a diagrammatic representation of the conclusions which will be discussed in this chapter.

The research question was answered with the help of the subsidiary questions; *the motivation to participate in the group, the perceived benefits of participation in a support group, the impact of support group membership on self management activities and when, in their illness trajectory do individuals become motivated to join a support group.*

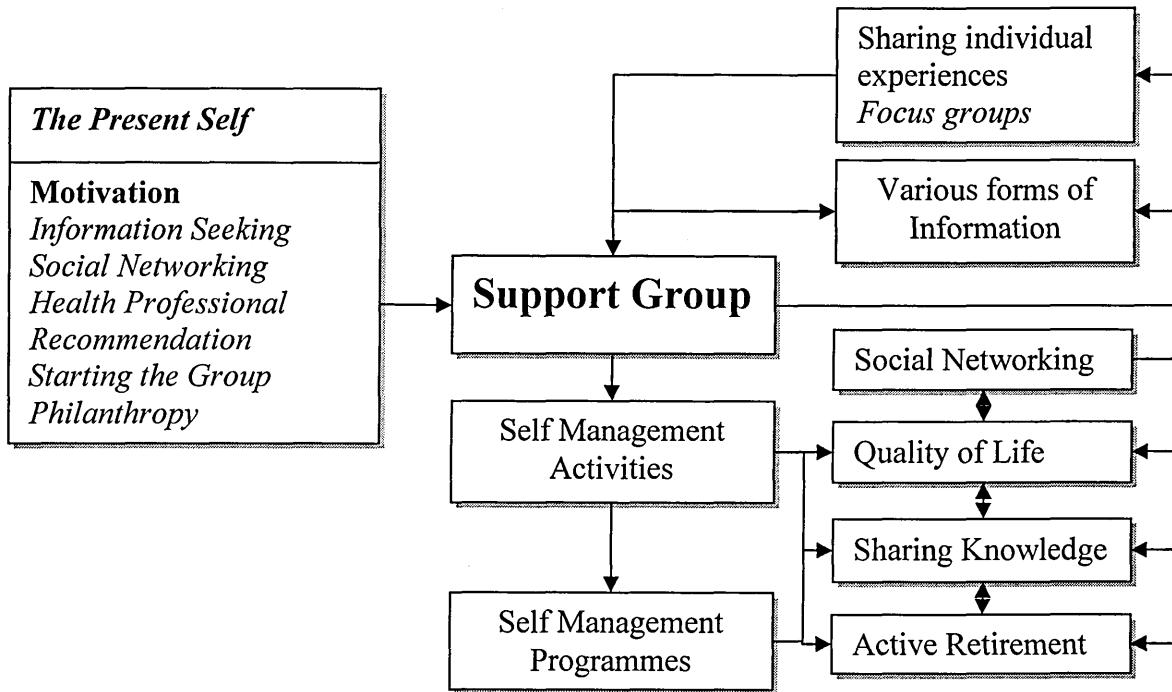


Figure 11.1 the purpose of support groups

A number of the outcomes of group membership shown in (figure 11.1) are bi-directional, these include; active retirement which impacts on quality of life and obtaining information and sharing knowledge and experience such as in the focus group organised by Arthritis Care.

11.1 Motivation to Join a Support Group

The interview participants identified that their motivation to join a support group included; *information seeking, increasing social networks, recommendation of healthcare professionals and starting a group*, these factors have been reported previously in the reviewed literature in chapter three. Philanthropy was reported by three of the interview participants and was identified as providing them with a social role which impacted on their quality of life.

Motivational factors identified by the interview participants were not always singular. There was evidence from the analysis of the interview transcripts and observational notes of primary and secondary factors. This was not recognised in the study by Subramanian et al (1999).

11.1.1 The Three Selves of Chronic Pain

Analysis of the interview and observational data helped in the identification of the *three selves of chronic pain* including; *the past, chronic pain* and *present*, an individuals' location in these selves is a salient point for the motivation to join a support group. The *present self* is the location in the chronic pain trajectory which this current study identifies as the *self* that would benefit the most from membership of a support group. Those who are experiencing the *present self* are dominant amongst the membership of all three groups. The Fibromyalgia group provided further evidence for this and helped to illustrate the importance of the recognition of the *three selves*. This group had the largest influx of new members and the majority were newly diagnosed and as such within the healthcare system. This study has recognised that this aspect of an individuals' trajectory is conducive with the *chronic pain self*.

11.1.2 Information Seeking

Information seeking as a motivational factor is more complex than the reviewed literature in chapter three suggested. Those who identified information seeking as a motivation were in actual fact seeking additional information to that provided in the healthcare system. This is reported by Hatzidimitriadou (2002) as why support groups were initially formed, as an alternative to existing treatment.

The support groups broadcasted written information in a number of formats including *factual* and *lifestyle*. In the MS and Arthritis groups' *lifestyle* information was the more popular with factual information being described as *dry* and not offering anything new. The identification of the appropriateness of information to the needs of the individual is an indication of a transition into the *present self*. In contrast to the factual information the lifestyle format was described as inspirational as well as creating awareness of hobbies or interests that may benefit through distraction from the pain. The lifestyle approach to broadcasting information also used *real person narrative* which discussed approaches to self management which were also popular.

11.1.3 Increase in Social Network

Increasing a social network was also a complex motivational factor which the reviewed support group literature did not report. The Department of Health (2001) recognised that chronic pain has the potential to cause social restrictions which impacts on individuals with many experiencing anger, bitterness, depression and despair. Social restrictions for older adults can impact on their loneliness and isolation which can contribute to the loss of a social role and as a consequence their quality of life. There was evidence from this study that support group membership was used by individuals as a preventative measure to safeguard against the potentials of isolation and loneliness. Members of one of the sampled groups set up an informal outreach programme. It was also reported that being with others in similar health and social circumstances prevented individuals from having to explain themselves particularly if the chronic pain impacted on mobility.

11.1.4 Healthcare Professional Recommendation

In the reviewed literature it was reported by Hildingh and Fridlund (2001) that information regarding support groups given by healthcare professionals resulted in relatively high figures of participation. However in this study the recommendation to join a support group by a healthcare professional was not successful. The belief that exposure to others in similar circumstances would benefit the individual can be positively reinforced through awareness of an individual's location within their chronic pain trajectory. Those who are still hoping for a cure are located in the *chronic pain self* which is not conducive to support group membership. The *chronic pain self* is not responsive to alternative approaches of self management which are identified as a benefit from membership of a support group.

11.1.5 Starting a Support Group

In the reviewed literature there is evidence that having professional input is not a guarantee of a successful support group (Adamsen and Rasmussen, 2001; Carlsen, 2003; Marzen-Groller and Bartman, 2005). The reason is that the purpose of the group can be contrasting between the peer and the professional. This would further suggest the need for professionals and individuals who are contemplating starting a group should be made aware of the existence of the *three chronic pain selves*. The potential outcome for this would be a productive partnership between the groups and the professionals the result of this would be; the referral of people who would benefit from group membership from primary and secondary care, a more effective advertising campaign by the groups. There would also be an established relationship which would result in affective communication regarding any changes to the group meetings.

11.1.6 Philanthropy

Philanthropic reasons have not been reported in the reviewed support group literature. These were often interwoven with other motivational factors. There is evidence that philanthropy benefits an individual through their perception that they are giving something back to society.

11.3 Benefits of Group Membership

In the reviewed literature in chapter three the benefits of support group membership were identified as an opportunity for people with a common problem to come together (Subramaniam et al, 1999; Munn-Giddings and McVicar 2006; Butow et al, 2007).

There is also the assumption that people facing similar challenges can help each other simply by coming together (Davidson et al, 2000). Individuals can share their experiences and concerns (Subramaniam et al, 1999). Individuals can gain personal, interpersonal and collective benefits which include improved self esteem, self confidence and mutual support (Munn-Giddings and McVicar, 2006)

This current study identifies additional benefits of group membership (figure 11.1, page 375) including access to various forms of information and an increase in their self management activities. Sharing individual experiences was more likely to take place in smaller informal groups as it was not encouraged during the group meetings. The reason for this was the limited time that was available. There was also evidence from the interview participants that smaller group were a forum for *sharing knowledge*. In this study the interview participants reported that aspects of membership of the support groups helped to contribute to an active retirement and also contribute to their quality of life. These included the opportunity to sit on the group's committee, participate in

charitable collections and for one of the sampled groups participate in a self management programme.

The lifestyle information provided by the groups inspired members to self manage aspects of their symptoms as well as think about other interests they could pursue. This was further punctuated by the choice of guest invited to speak at the meetings.

11.4 The Sampled Groups

In this current study there were elements of the various groups which were reported in reviewed literature in chapter three. The groups observed in this current study met the criteria of the operational definition identified in chapter four, page 171. These definitions included 1) groups that were peer led 2) groups with no or limited professional input 3) groups that meet regularly but do not require regular attendance 4) groups that do not have a limited length of membership.

There was a lack of evidence that the groups in this current study resembled the characteristics posited by Adamsen and Rasmussen (2001) of spontaneous anti-bureaucratic organisations. Spontaneity was not the case for the Fibromyalgia group which took several months to establish due to identifying a suitable venue for the meetings. The Arthritis group was a reincarnation of several failed groups. Failure was blamed on two important factors including; the upper age of the original group members and the lack of focus as to the purpose of the group.

The consequence of the affiliation that the groups had with national charities did not reduce bureaucracy this is reflected in the number of procedures and constitutions that needed to be implemented by the groups.

The MS group was comparable to the exercise and dance groups that were the focus of the study by Paulson (2005). The primary focus of the MS group was also socialisation as well as emotional support. The potentials of the disabling nature of multiple sclerosis and the impact that this could have on isolation and social exclusion helps in understanding the group's focus. There was also an element of the informal social group studied by Cheang (2002).

The Arthritis group initially resembled elements of Cheang's (2002) studied group. At the beginning of the observation period socialisation appeared to be the primary aim. There was a deficit of guest speakers and members did not appear to refer to their health in the meetings. Mary reported that each of the tables of four within the meeting room held *micro* groups.

The Fibromyalgia group was the closest to the operational definition in that there was an identifiable purpose from the onset of the observation. The group was also strongly based on advocacy as well as creating awareness of the illness. The need to broadcast quality information was also the focus of the group's activities.

In summary this partial feminist ethnographic study developed novel information to increase understanding of what motivates older adults to participate in support groups. Perceived benefits of membership referencing the four components of social support reported by Langford et al (1997). The impacts that support groups may have on the self management activities of older adult members. In addition this current study also identified when in the chronic pain trajectory support group membership is beneficial. The next section will discuss future research based on the findings of this current study.

11.5 Future Research

The findings from the study and the lessons learnt from conducting it raise ideas for future research. Some potential areas are described below.

The study highlighted a wide variation in how the groups functioned while identifying key elements recognised as important by individual group members that include access to good quality sources of information including guest speakers and written information which is both factual as well as lifestyle based. An in-depth qualitative investigation focusing on this would provide more information that could be used to inform a framework for the successful establishment of support groups. Such a study would benefit from taking the perspective of users and purposively sampling existing groups across the UK with a range of sizes and history.

Presentation of the study (Welsh Pain Society meeting Chapter 10) raised an interesting discussion about the relative merits for older people with chronic pain of support groups and formally structured self-management programmes such as the Expert Patient Programme.

Observations were highlighted in which some patients had reported that they did not want to invest in a programme which demanded a high level of commitment and time. In the reviewed literature Kerns and Habib (2004) have reported additional issues with self management programmes. These include the expense of the programmes with a high dropout rate and a failure to engage with the recommendations. Others have also criticised their *off the shelf* and *prescriptive* nature (Koch et al, 2004). Further work could be carried out to see if the different, perhaps less formal and more slow-paced, format of support groups could be a more acceptable method of delivering self-management training for some older people with chronic pain. Initial work in this area would by necessity be qualitative to establish the feasibility of methods of delivery for example. Such developmental work would pave the way ultimately for a randomised controlled trial to address the question from an additional quantitative perspective looking at clinical and cost effectiveness.

There is also scope for study into how support groups and self-management programmes could complement each other. Already, support groups have been identified as sources for recruiting potential participants to self management programmes (DoH, 2001). The identification in this current study of the three selves of chronic pain in support group members could be developed further with the aim of helping to identify group members who would be likely to engage with self-management programmes most readily.

Presentation of the study (British Pain Society Chapter Ten, page 367) raised a further issue about the need to create awareness of support groups among healthcare professionals, who often reported as misunderstanding their purpose of groups using labels like '*The Moaners and Groaners Club*'. In chapter four , for example, I reported that my previous experience of support groups was an awareness of their existence but not their function. An initial qualitative study could explore the range of awareness of health professionals and their opinions of current and potential roles of support groups for older people with chronic pain. Again this would be most useful as a UK wide study purposively sampling health professionals from a range of professional backgrounds, clinical experience and attitudes and beliefs about older people with chronic pain. That study could inform the development of a questionnaire that could add to the knowledge from a quantitative perspective.

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Appendix 1 - Cognitive Coping Strategies

Cognitive Coping Strategies
<p><i>Diverting Attention:</i> Thinking of things that serve to distract one away from the pain.</p> <p>Sample item: I count numbers in my head or run a song through my mind</p>
<p><i>Reinterpreting Pain Sensations:</i> imaging something, which if real, would be inconsistent with pain</p> <p>Sample item: I just think of it as some other sensation such as numbness</p>
<p><i>Coping Self Statements:</i> telling oneself that one can cope with the pain, no matter how bad it gets.</p> <p>Sample item: I tell myself to be brave and carry on despite the pain</p>
<p><i>Ignoring Pain Sensation:</i> denying that the pain hurts or affects one in any way.</p> <p>Sample item: I tell myself it doesn't hurt</p>
<p><i>Praying and Hoping</i> – telling oneself to hope and pray that the pain will get better some day</p> <p>Sample item: I pray to God it won't last</p>
<p><i>Catastrophising:</i> negative self statements, catastrophising thoughts ideation</p> <p>Sample item: I worry all the time about whether it will end.</p>
Behavioural Coping Strategies
<p><i>Increasing activity level:</i> engaging in active behaviours which divert one's attention away from the pain.</p> <p>Sample item: I do something active, like household chores or projects.</p>
<p><i>Increasing Pain Behaviour:</i> Overt pain behaviours that reduce pain sensations.</p> <p>Sample item: I take my medication</p>
Effectiveness Ratings
1. control over pain
2. ability to decrease pain

Listing of sample items in the coping strategies questionnaire by strategy subscale

(Rosenstiel and Keefe 1983)

Appendix 2 - Letter to Support Groups

[University headed paper]

Dear *Group Leader*

I am a PhD student at Sheffield Hallam University. The focus of my study is support groups for people experience chronic pain or long-term painful conditions such as [fibromyalgia, arthritis]. I have a particular interest in people who are aged 55 years and older who attend the group meetings.

In the study I would like to participate and observe a number of group meetings in order to understand why people join the groups, the support activities available and if participation in a support group contributes to the management of their pain. I would also like to interview members of the group who are aged 55 years or older and ask them about the support group as well as their chronic pain experience. The interviews will be transcribed verbatim and discussed with the participant for accuracy, anything that they would like removed or changed will be. Notes that I have made at the meetings will be used in the final thesis but will be discussed with the group members to ensure that I have made correct interpretations of the group. Anonymity and confidentiality of the group, the members and interview participants will be preserved by removing identifying factors such as names of places and the people involved. The participants of the group are also free to remove or ask me not to use anything that they may find sensitive.

This study has been reviewed and approved by Sheffield Hallam University's ethics committee. If you require any further information please contact on the 'phone numbers

or e-mail address below. I can also supply you with contact details of my academic supervisors should you need to confirm with them the legitimacy of this study. I will share the results of the study with the group and the interview participants and anything that the group or interviewee would like removing from the results will be.

I look forward to hearing from you.

Kind regards

Mr Paul Sykes

PhD student,

Appendix 3 – The Interview Schedule

Thank you for agreeing to this interview. I would like you tell me in your *own words* what your life is like with chronic pain both before and after attending the *support group*.

The support group:

I am going to ask you some questions about the support group

- Can you tell me about joining the group e.g. where did you hear about the group? Why did you join?
- What are the benefits of being a member of the group e.g. information, support from others?
- Can you tell me if the group or anything such as techniques you have learned at the group has had any impact on how you manage or cope with your pain?
- Is there anything else that the group has contributed to or made you aware of approaches to your management or coping with your pain?

Chronic Pain

I am now going to ask you about your chronic pain

- How many years have you been experiencing chronic pain?
- When did you join the support group
- What impact has your pain had on family and friends? E.g. diminished social network. Reduced support through misunderstandings?
- Were you provided with information about chronic pain from the National Health Service (or other formal healthcare organisations)?
- Was the information useful?
- Was important for you to be with others in similar situations?

Appendix 4 – Sample Transcript Analysis (information gathering Mary)

M: yeah and I said er er look its that bad I'll pay for a consultation erm I think its about a hundred and twenty quid or something and erm I described all the symptoms and he said oh that's psoriatic arthritis and then when I got the booklet¹ which tells you about it it classic cos I was saying you know the me left er wrist aches a lot more than my right wrist²

I: mm

M: and I don't you know why should it because I'm right handed and that's classic symptoms³ so it (short pause) and I think then erm I went to see (short pause) oh I can never remember her name (name) (name) the rheumatology nurse⁴

I: oh yes yeah

M: yeah I went to see her and (husband's name) came with me gave me a load of gumph⁵ about it erm and then they said that there was this support group that had just started erm and I went to the second meeting which was at the fire station

I: mm

M: erm and and I thought oh well I'll just go and see what its about and I got quite interested because I could find out from other people

¹ Information from formal healthcare system

² Use of information

³ Information provision increases the need for more information

⁴ Information source – healthcare professional

⁵ Unhelpful information – quality?

who had got a similar condition to me⁶ erm and I could find out about how they felt and the problems they were having and then erm being involved with the group and being part of the erm arthritis care you then get the the er magazines and some articles in there that I'm thinking it isn't me its not me that's being a girly wuss⁷ and thinking oh what's the matter with you get on with get on with life you know⁸

I: mm mm

M: erm and you its helped me find out more information about me condition and I think its also helped me be more realistic about me condition as well but erm⁹

I: and also it might have helped you know seeing these articles then it could help (husband's name) sort of understand what your going¹⁰through I suppose couldn't it?

M: yeah it does and he he er I mean he's very good and he moans at me cos one of the things with erm this type of arthritis is the fatigue¹¹ and er erm several articles that I've I've read that says that fatigue is more difficult to cope with sometimes that the pain erm and its like¹²

⁶ Recognition of other information sources

⁷ Other sources of information

⁸ Use of information

⁹ Recognition of the purpose of the support group for her was information and how useful this was in realism and future management activities

¹¹ Partner helps in the management through the provision of an external locus of control

¹² More information gathering

o:::hh I'm so tired well sit down he'll says well sit down no I'll just go
and tidy the kitchen or I'll just go and this will you sit down (laughs)¹³

¹³ Partner helps with pacing

Appendix 5 – Presentation to the Aberdeen Pain Group

Slide 1

The slide has a white background with a dark grey border. At the top center, it says "Joining a Self Help Group". Below that, "Paul Sykes" and "PhD Student" are listed. In the bottom left corner, there is a small logo for "Sheffield Hallam University" with the text "www.shef.ac.uk/uniweb" below it.

Slide 2

The slide has a white background with a dark grey border. At the top center, it says "PhD Thesis". Below that, "Title: An Ethnographic Study of Support Groups; the Pain Narratives of members" is listed. Under "Aims:", there are two points: 1. To explore the general pain narrative of group members and 2. To understand what support groups offer.

Slide 3

The slide has a white background with a dark grey border. At the top center, it says "Introduction". Below that, a bulleted list details the methodology: Participants were identified from 3 support groups (Arthritis Care, Multiple Sclerosis Movement and Fibromyalgia); All groups were easy to locate via the internet, charities, council lists and flyers in hospitals and GP Surgeries; Data was obtained from: observational field data and pain narratives of 9 participants.

Slide 4

Interviews

- 9 volunteers (7 women and 2 men, aged 59 plus)
- Semi-structured
 - pain history
 - self help group history
- Interviews took place in participants homes
- 1 – 2 hours to complete

Slide 5

Coding

- Environment – etiquette, meetings, venue
- Experience – other groups
- Contact and Entry - finding group, first meeting, joining, perceptions
- Group Membership – extra role, influence., retention, socialising, verifying, wish list
- Group Purpose – adv/disadvantages, future, origins, services, politics and lobbying
- Institutions – the charity, the NHS
- People – leaders, members, non-members, professionals, younger people, family

Slide 6

Why a self help group?

- Butow et al (2007). top 4 reasons for joining SG:
 - Knowing you are not alone
 - Hearing about current medical research
 - More informed about side effects and coping
 - Learning how other people cope
- Voerman et al. (2007) reasons for interest in SG:
 - Lack of social support
 - Age (lower age)
 - Attitude
 - perceived control of illness

Slide 7

Why a self help group (2)?

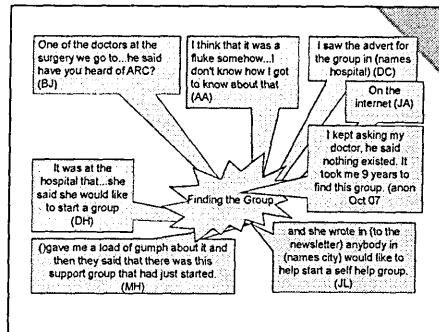
- However this study showed:
 - Altruism
 - Medical professional interest (Carlsen, 2003)
 - Use it or lose it
 - Information
- Dibb and Yardley (2006) social comparison
- Why don't you join (Bui et al. 2002)?
 - enough support already
 - live too far away
 - have no need

Slide 8

Contact and Entry from this Study

Here are some quotes from interviews and field notes which relate to contact and entry

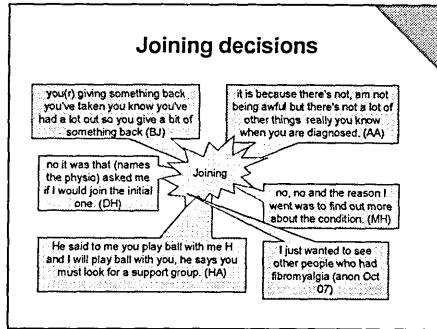
Slide 9



Of the 7 who commented about finding the group.

- 3 were told about the group by health professionals
- 3 found the group via strategic advertising
- 1 found the group via the internet
- 1 found the group from word of mouth

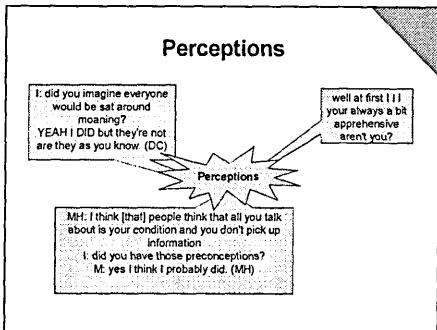
Slide 10



5 respondents commented on joining the support group for the following reasons:

- Giving something back
- Use it or loose it
- 2 from medical professionals advise
- the need for further information

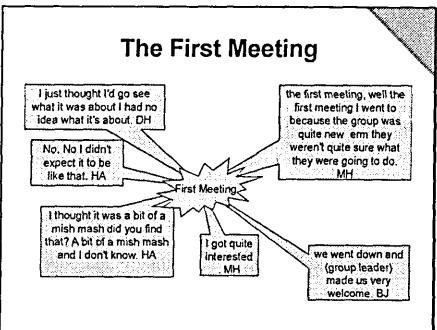
Slide 11



Just 3 respondents commented on pre-meeting feelings.

- Stereotyping
- Emotional

Slide 12



Conclusions

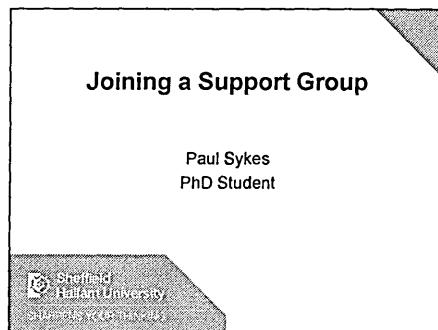
- Work on 'medicalised' support groups mainly focuses on cancer.
- There is a lack of literature with regards to the processes surrounding the reason to join.
- Professional influences in the decision join should not be underestimated.

References

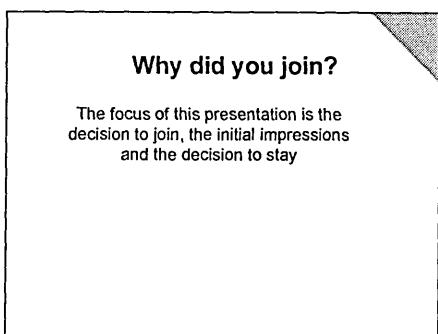
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Appendix 6 - Presentation Welsh Pain Society

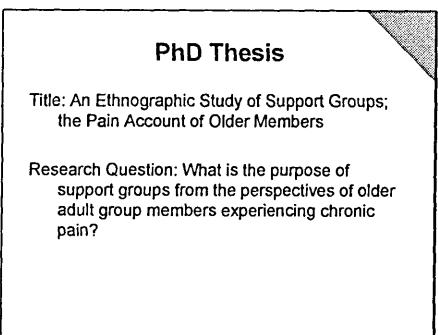
Slide 1



Slide 2



Slide 3



Slide 4

Research Aims

Main Research Aims:

- To understand the purpose of support groups
- To explore the pain accounts of older adult group members

Slide 5

Obtaining Data

- Exploration of a group or culture suggests that ethnography is a logical methodology
- Data was obtained from:
 - participant observation
 - group artefacts
 - semi-structured interviews of older group participants

Slide 6

Introduction

- Three chronic illness support groups in Northern England were identified:
 - Arthritis Care (1)
 - Multiple Sclerosis Movement (2)
 - Fibromyalgia (3)
- Groups were located via flyers in medical centres/hospitals, National Charitable Organisations internet sites and word of mouth

Slide 7

Group Biographies

- All groups are affiliated to a NCO
- Fibromyalgia (FM) and Arthritis Care (AC) groups were started by medical professionals
- Multiple Sclerosis (MS) movements meets weekly
- FM and AC meet monthly
- All the groups are set up to provide information and support for professionals, individuals and their families and carers

Slide 8

Core Membership

- Core members of a group are identified as those that attend each meeting
- AC had the largest core membership (14)
- Interview participants were sampled from the core membership
- MS had no new members join
- FM had the largest number of new members and also one meeting attendees

Slide 9

Observation Period

- It was intended that the participant observation phase of the study would be one calendar year:
 - Arthritis Care
 - MS movement - 3 months
 - FM - 10 months
- Group artefacts:
 - Newsletters
 - minutes from meetings
 - written information

Slide 10

Interviews

- Semi-structured
 - pain history
 - self help group history
- Participants were aged 59 to 78 years
- Interviews took place in participants homes
- 1 – 2 hours to complete

Slide 11

Reporting the Findings

The presentation of the findings revolve around:

- Group practicalities
 - Venue, meeting times, room layout, meeting format
- The people
 - Leaders, members, speakers
- Interview participants accounts of their pain

Slide 12

Reasons for Interest in a Support Group

- Voerman et al. (2007) reasons for interest in SG:
 - Lack of social support
 - Age (lower age)
 - Attitude
 - perceived control of illness

Slide 13

Why Join a Support Group?

- Butow et al (2007). top 4 reasons for joining SG:
 - Knowing you are not alone
 - Hearing about current medical research
 - More informed about side effects and coping
 - Learning how other people cope

Slide 14

Reasons not to Join

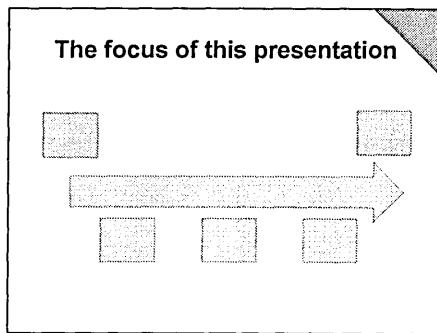
- Why don't you join (Bui et al. 2002)?
 - enough support already
 - live too far away
 - have no need

Slide 15

In this Study

- The top 4 reasons as:
 - Medical professional interest (Carlsen, 2003)
 - Information gathering
 - Altruism
 - Use it or lose it
- There was also strong evidence of social comparisons (Dibb and Yardley, 2006)

Slide 16



Slide 17

Participant Biographies				
B1	Rheumatoid Arthritis	25 years	5 years	Foundry Worker
D1	Rheumatoid Arthritis	20 years	5 years	SRN
M1	Psoriatic Arthritis	15 years	5 years	Corporate Trainer
A2	Trigeminal Neuralgia	15 years	6 years	Lunch Supervisor
H3	Fibromyalgia	18 months	2 weeks	RMN/RMN
J3	Fibromyalgia and amputation of toe	10 years	9 years	Civil Servant
C3	Fibromyalgia	30 years	9 years	Fitness Instructor
J3a	Fibromyalgia	25 years	8 years	Administrator
D3	Fibromyalgia	25 years	3 years	Banking

Slide 18

Locating – Medical professional influence	
• It was at the hospital that...she said she would like to start a group (D1)	
• One of the doctors at the surgery we go to...he said have you heard of ARC? (B1)	
• She [the nurse] gave me a load of gumph about it [the illness] and then they said that there was this support group that had just started. (M1)	
• I kept asking my doctor, he said nothing existed. It took me 9 years to find this group. (FM anon)	

Slide 19

Locating - Advertising

- On the internet (J3A)
- I saw the advert for the group in [names hospital] (D3)
- and she wrote in [to the newsletter] anybody in [names city] would like to help start a self help group. (J3)
- Other
 - I think that it was a fluke somehow...I don't know how I got to know about that (A2)

Slide 20

Summary

- Medical professionals help to provide information about support groups
- Advertising of the groups is also an important element

Slide 21

Joining – Medical professionals

- no it was that [names the physio] asked me if I would join the initial one. (D1)
- He said to me you play ball with me H and I will play ball with you, he says you must look for a support group. (H3)

Slide 22

Joining – Information

- The reason I went was to find out more about the condition (M1)
- I just wanted to see other people who had fibromyalgia (anon FM)

Slide 23

Joining – other reasons

- you[re] giving something back you've taken you know you've had a lot out so you give a bit of something back (B1)
- it is because there's not, am not being awful but there's not a lot of other things really you know when you are diagnosed [with MS]. (A2)

Slide 24

Summary

- There are push and pull factors
- Medical professionals can be a push factor
- The need for information about the condition is also a pull factor
- Knowing you are not alone is another influence but does not mean that attendees remain group members

Slide 25

Negative Initial Perceptions

- M1: I think [that] people think that all you talk about is your condition and you don't pick up information
- I: did you have those preconceptions?
- M1: yes I think I probably did.
- well at first I I you're always a bit apprehensive aren't you? (J3A)
- I: did you imagine everyone would be sat around discussing the illness?
- YEAH I DID but they're not are they as you know. (D3)

Slide 26

Summary

- Only a small number of participants had initial impressions about what a support group was
- These initial impressions for the interview participants were unfounded
- Where the initial impressions of the new attendees unfounded?
- Is there a need to overcome these impressions?

Slide 27

The first meeting

- I just thought I'd go see what it was about I had no idea what it's about. (D1)
- the first meeting, well the first meeting I went to because the group was quite new erm they weren't quite sure what they were going to do but I got quite interested. (M1)
- we went down and [group leader] made us very welcome. (B1)

Slide 28

The First Meeting - negative

- No, No I didn't expect it to be like that. I thought it was a bit of a mish mash did you find that? A bit of a mish mash and I don't know. (H3)

Slide 29

Summary

- The first meeting is the test for many new members
- Initial impressions for some can fade during the first meeting

Slide 30

Conclusions

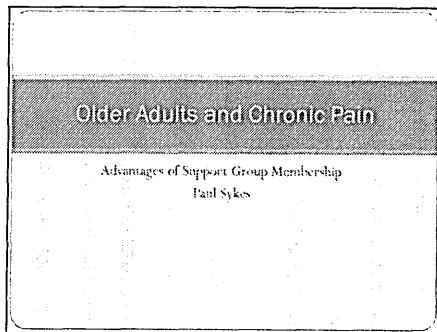
- Previous work on medical support groups focus mainly on cancer
- There are many factors that can influence a person to join a support group. This study demonstrates that loneliness is not a contributing factor
- Preconceived ideas need to be overcome
- Medical Professionals can influence the decision to join but the decision to stay is individual

References

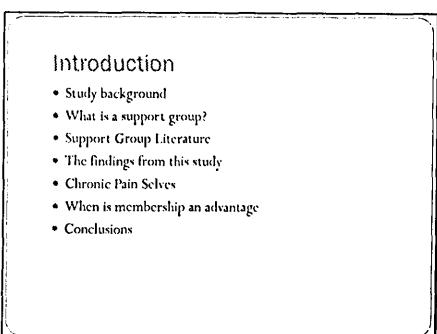
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Appendix 7 – Presentation to the British Pain Society Meeting

Slide 1



Slide 2



Slide 3

Study Background

- Qualitative study - Ethnography (group observation, semi-structured interviews)
- Three support groups sampled
 - Arthritis
 - Fibromyalgia
 - MS Movement
- Exploration of the pain accounts of a sample of older adult support group members

Slide 4

Biographies of the studied Groups

- All located in urban areas of the North of England
- All offered help lines
- Arthritis – monthly meetings, affiliated to a NCO
- MS movement – weekly exercise group, affiliated to a NCO
- Fibromyalgia group – monthly meetings affiliated to a NCO
- All had casual membership
- All were open groups
- MS and Arthritis had minimal professional input

Slide 5

What is a support group?

- USA – multiple titles – mutual aid, self help and support groups
- UK – Self help, support groups, support in unexpected venues e.g. Over 50 exercise groups
- Confusion within the literature
 - Support groups involve expert leaders and have closed membership (Hollieon and Gottlieb, 2000; Munn-Giddings and McVicar 2006)

Slide 6

What is a support group?

- According to Charlton and Barrow (2002) – self help groups are facilitated by professionals and support groups are facilitated by members. Adamsen and Midgaard Rasmussen (2001) define groups as anti bureaucratic organisations, spontaneous, reciprocal, encouraging personal participations without professionals
- Although support groups can have minimal professional involvement (Shepherd et al, 1999)

Slide 7

What is a support group

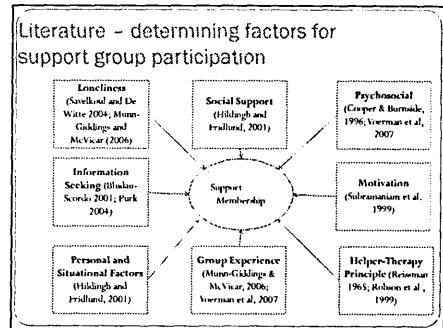
- Munn-Giddings and McVicar – suggest that a group is identified by the term that the members and group leaders use
- For the purpose of the study a hybrid of the literature definitions of the groups were used
- Support groups in this study had minimal professional input and were largely led by group members and were open

Slide 8

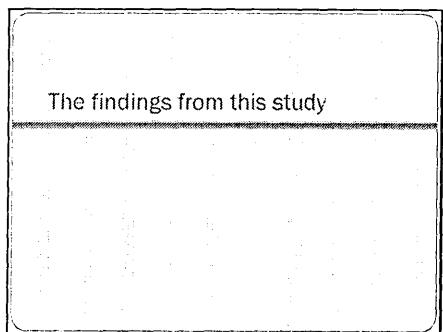
Literature

- There is very little attention paid to older adults and support groups
- Focus on dementia, Parkinson's disease or carer issues

Slide 9



Slide 10



Slide 11

Interview Participant Biographies					
	Participant	Diagnosis	Length of Illness	Employment	Education
Brian	RA	25 years	5 years	Fulltime Worker	
Janet	Brian's Wife	N/A	5 years	Part-time Caregiver	
Deidre	RA	10 years	5 years	SKIN	
Mary	Osteoarthritis Arthritis	6 years	5 years	Corporate Trainer	
Allison	MS/Trigeminal Neuralgia	15 years	6 years	Lunchtime Supervisor	
Hilary	FM	18 months	2 weeks	RN/MSN/MHN	
Jen	FM	10 years	9 years	Civil Servant	
Clare	FM	30 years	9 years	Fitness Instructor	
Joe	FM	25 years	8 years	Admin	
David	FM	25 years	3 years	IT - Bank	

Slide 12

The Study Findings

- Informational Deficit/exhaustion within the formal healthcare system
- Social Networking Opportunities
- Philanthropic
- Suggestion of medical professional
- Started the group
- Reason for membership to elements from all the above

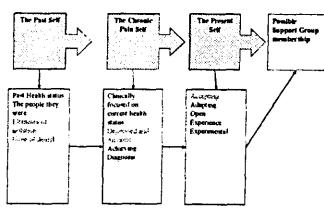
Slide 13

Chronic Pain Selves

- Emerged from the accounts were data that suggested a elements of the process similar to Kübler-Ross (1969) work on death and dying
 - Denial and Isolation
 - Anger
 - Bargaining
 - Depression
 - Acceptance

Slide 14

Chronic Pain Selves



Slide 15

Study Participant - Advantages

- Informational support through exchange of experiences
- Information gathering was subjective, elements from trusted sites on the internet (NCO web pages and links), lifestyle magazines, guest speakers, reading list exchanges

Slide 16

Study Participants – Advantages

- Social support, telephone helpline, welfare officer
- Newsletters
- Corresponding with isolated members
- Occasional gatherings
- Support needs of partners and carers

Slide 17

Study Limitations

- Small sample
- Groups were not chronic pain focused but medical
- Talking about own experiences was discouraged within the groups
- None chronic pain discourse – only in satellite groups
- Groups within urban setting

Conclusion

- Although social support was reported the groups were not the sole source of socialisation for any of the interviewed participants
- Although one group experienced both in and out groups in terms of socialisation
- Elements of Expert Patient Programme
 - Education – speakers, differing formats of information broadcast
 - Self management – pacing, opportunities to attend Challenging Arthritis
 - Contributions to life quality
