

Weight Gain following a stroke in Younger age (below 70) men and women:

Challenges and opportunities for prevention and action

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Executive Summary

Introduction

This report presents findings from a study to explore the incidence of weight gain in working age adults aged men and women in South Yorkshire. The research was funded by Research Capacity Funds from the National Institute for Health Research, Collaboration for Applied Health Research and Care South Yorkshire (NIHR CLAHRC SY). The project was developed following a research prioritisation event focused on obesity. The event was conducted with staff from a range of stakeholder organisations including health, social care, and voluntary sector.

Methods

Data collection took place between August 2013 and March 2014. A survey was sent to respondents of the South Yorkshire Cohort (Relton et al 2011) who were under 70 years old and had had a stroke. In-depth interviews (n=12) were carried out with patients responding to the survey living in Sheffield and participants from a local volunteer run stroke support group for working aged people. In-depth interviews were also undertaken with professionals (n=18) working across the stroke service pathway in Sheffield. Framework analysis techniques were adopted.

Findings

The research demonstrated that long term weight gain is an issue for some patients following their stroke. Interviews with patients highlighted a range of lifestyle related challenges that people face following a stroke. Reduction in activity levels was reported as a key influence on weight gain.

The health care system and stroke pathway currently provides short-term support to patients to aid recovery and rehabilitation. Longer-term support is harder to access. Existing and new support networks provided by health services, family and friends are essential in recovery and prevention of weight gain. Interviews with staff revealed gaps in their knowledge of their colleagues' roles across the stroke care pathway. Communication between health care professionals across the care pathway was also limited. The presence of patients who gain weight following a stroke was not evident across the entire stroke pathway for example staff in the acute setting were less likely to notice weight gain. Not all staff gave health promotion advice to patients, however all staff thought health promotion advice should be offered to patients, at a time appropriate to the individual and in a manner that will engage the patient in behaviour change. Staff highlighted the need to engage family members in a patient's rehabilitation to prevent long term weight gain.

Key Messages

- The long-term effects of stroke on weight gain are complex. Eating and activity behaviours and social isolation all play a part. Reduction in activity levels was a key influence
- The long-term physiological and psychological impacts of the stroke challenge patients in controlling lifestyle and diet change following their stroke
- The presence and nature of families and social networks before and after a stroke influence weight gain
- Timing of health promotion advice needs be patient centred
- Integrated care pathway can play a part to improve communication between health professionals and patients

Chapter 1: Introduction and background

Introduction

This exploratory study aimed to explore the rehabilitation and weight management experiences of stroke survivors under 70 years of age in the South Yorkshire locality. The purpose was to identify whether weight gain is a problem for people following a stroke, and if so what factors contribute to weight gain.

This is an initial exploratory study that was developed following discussions during coproduction, research prioritisation events run by the obesity theme within Collaboration for Leadership in Applied Health Research and Care, South Yorkshire (CLAHRC SY). Pre-protocol consultation with academics, voluntary sector and health and social care practitioners supported the need for the research.

The report is structured as follows:

- Chapter 1 details the purpose of the study and background
- Chapter 2 includes the study aim and research questions
- Chapter 3 describes the methods employed
- Chapter 4 presents the findings from the survey, patient and staff interviews
- Chapter 5 concludes the report and highlights key messages from the research

Background

Stroke

A stroke occurs when the blood supply to the brain is impaired due to a blood clot or a bleed. A stroke can have a long or short term negative impact on cognition, sight, mobility or communication. 150,000 people have a stroke in the UK each year (Stroke Association, 2012). In 1999, strokes accounted for over 56,000 deaths in England and Wales (Mant et al 2004). In developed countries stroke is the third leading cause of death after heart disease and cancer and is the leading cause of long term disability (Curioni et al, 2009). Approximately a quarter of strokes occur in people of working age, under 65 years (DH 2007). Survival rates following a stroke are increasing, and upwards of 900,000 people in England live with the effects of a stroke (NICE 2010). Whilst the wider economic and societal costs of a stroke are approximately £7 billion per year, £2.8 billion of these costs are picked up by the NHS (Mant et al 2004). The Department of Health's (DH) response to these figures was outlined in a National Stroke Strategy developed in 2007 (DH 2007), which included ambitions for the diagnosis, treatment and management of stroke.

Risk factors for a stroke are split into three categories (Goldstein et al 2001): non modifiable (age, ethnicity, gender, family history); modifiable (includes hypertension, other cardiac disease, diabetes); and, potentially modifiable (obesity, smoking, physical inactivity, drug and alcohol use, hormone replacement therapy and oral contraceptives). Some modifiable risk factors, such as high blood pressure and cholesterol, are linked to lifestyle factors including smoking, low physical activity levels, poor diet and excessive body weight (Kurth et al 2005). Dietary factors, including low levels of fruit and vegetable intake (below 600g per day), and excess salt consumption can impact upon stroke risk. Poor diets are therefore important in primary and secondary prevention of stroke. Adopting or maintaining a healthy lifestyle after a stroke will help to minimise these risk factors.

There is much debate concerning how overweight manifests as a risk factor for stroke. The incidence of stroke is higher in obese people with hypertension or diabetes (Curioni et al 2009). The American Stroke Association guidelines for stroke prevention include being overweight as a risk factor for stroke. The guidelines also advise keeping weight following a stroke to a target body mass index (BMI) of 18.5-25 kg/m² (Goldstein et al 2006). Kurth et al (2005) highlight a number of papers suggesting obesity as a risk factor for ischemic stroke. However, a Cochrane review, reported that the evidence of an association between obesity and stroke is inconclusive (Curioni et al 2009). Additionally, analysis of clinical data suggests being overweight following a stroke also has benefits for stroke survival (Scherbakov et al 2011). The findings of this research conflict with messages promoting weight management to improve health and reduce the risk of cardiovascular risk. Scherbakov and colleagues (2011) refer to 'the obesity paradox', whereby the impact of being overweight is different in the healthy population to the outcomes of those with chronic cardiovascular disease. They suggest weight management recommendations for patients with chronic illness may need to be different from recommendations made in primary prevention settings, and call for more evidence to be developed from interventional studies.

Modification of health behaviour can be crucial in stroke rehabilitation and in preventing avoidable long term impairment. Rehabilitation is acknowledged as being fundamental to maximising quality of life, independence, and well-being for individuals and their carers following a stroke. However, the success of stroke rehabilitation can be affected by the timing and quality of the information

given, as well as access to specialist services. 'Life after a stroke' was a key chapter in the DH National Stroke Strategy. The strategy highlighted the poor quality of and access to rehabilitation services post discharge from hospital. In the first six months, only half of stroke survivors were able to access services; this fell to one fifth in the subsequent six months (DH 2005). Health care and rehabilitation services are weighted towards delivery in the acute phase e.g. focusing on an initial 12 week pathway but only offering limited support thereafter. These services typically target older people and people with complex post-stroke care needs and co-morbidities. As three quarters of younger stroke sufferers want to return to work (Stroke Association, 2006), more evidence is required to understand the experiences of this age group and of people with a less severe stroke. Rehabilitation and recovery specifically targeting to these groups could help to improve quality of life of patients and reduce the costs to the economy and NHS.

The health behaviours and decision making of individuals following a stroke are influenced by existing habits and wider determinants of health such as: income; housing; environment; and, social factors (Niadoo and Wills 2000, Dahlgren and Whitehead 1991). Over the last four years there has been a greater demand for the commissioning of weight management services which support people to improve their diets and increase physical activity levels, whilst also tackling health inequalities. These services could be suitable for some stroke patients. However, local service review suggests they are not utilised by stroke patients and no direct referral from stroke rehabilitation services. Consultation with local expert stakeholders has identified a growing number of patients who are gaining weight as a longer term consequence following a stroke. Data from the South Yorkshire Cohort (SYC) identified that of the 212 people (aged <70 years) who reported having a stroke, 133 are overweight or obese but it is unclear whether this is as a result of the stroke.

Obesity

Obesity is considered a global epidemic and a national and international public health priority and challenge (James 2008, Nanchahal et al 2009, National Obesity Observatory 2010). The 2010 Health Survey for England indicates 42% of men are overweight and 28% are obese, whilst 32% of women are overweight and 26% are obese. Obesity rates in the UK have doubled over the last 25 years and it is predicted to become the most widespread public health concern for adults in the UK affecting 60% of men and 50% of women by 2050 (House of Commons Health Committee 2004, Government Office for Science 2007).

Obesity imposes serious health consequences through increasing the risk of developing type 2 diabetes, some cancers, cardio-vascular disease, and ultimately reduces life expectancy (World Health Organisation 1998, NICE 2006). Furthermore, there are negative social consequences of obesity including discrimination, low self-esteem, social exclusion and loss of working days, all of which impact on the wider economy (NOO 2010). Financial costs to society are estimated to be up to as much as £15.8 billion with UK NHS costs for treating obesity related conditions £4.2 billion (Government Office for Science 2007). Investing in prevention and treatment of obesity could therefore produce massive cost savings which are comparable to that of curing cardiovascular disease or diabetes (Wolfe and Smith 2002).

Obesity is caused by the imbalance of energy in (food consumed through diet) and energy out (energy used by the body to be physically active) (DH 2008). Individual level determinants such as knowledge, practical skills and attitude influence individual responsibility to maintain the balance and much research has concentrated on this area (National Obesity Observatory 2011). However, as above, it is important to take into account the wider social and environmental determinants on health (Niadoo and Wills 2000). Obesity has a number of complex roots (Dahlgren and Whitehead 1991). The Government Office for Science (2007) and DH (2008) suggest these wider determinants often make the healthy choice a hard choice. The relationship between socio economic status and obesity prevalence is an important focus for research (Sobal and Stunkard 1989). Whilst all social groups are affected by obesity, social drivers and the obesogenic environment will play out differently between populations (French et al 2001). Preliminary unpublished analysis of the South Yorkshire Cohort¹ (SYC) data indicates that all social groups experience overweight but obesity is more prevalent in deprived populations. This is reinforced by other studies (McLaren 2007, The Marmot Review 2010). Lower income affects the ability to engage in healthy lifestyle activities for example being able to afford or access healthier foods or access physical activity leisure pursuits (Drewnowski and Specter 2004).

An increased prevalence of obesity is also observed in women and men with fewer educational qualifications (National Obesity Observatory 2010). The National Obesity Observatory (NOO) briefing (2010a) and a systematic review by McLaren (2007) highlights the positive association between increasing levels of deprivation and obesity prevalence in women. Women with low incomes who want to lose weight are less likely to participate in weight loss programmes due to child care responsibilities, location, cost and availability of programmes (French et al 1998). Even where access and cost is not an issue (through free services), people with lower income and educational attainment find it more difficult than more educated counterparts to use combined approaches of increased activity and healthy eating to manage their weight (French et al 1998).

Research development

As the above literature indicates, the associations between stroke, weight and wider social determinants of health are complex. However, there is sufficient evidence to suggest that stroke recovery and secondary prevention would be aided by maintaining a healthy weight. Therefore this study was developed to help establish whether there are risks of weight gain following stroke and why these risks occur. The study will generate insight into the experiences of food and physical activity in a small cohort of people post-stroke who have experienced self-reported weight gain.

¹ The South Yorkshire Cohort is a research project that will follow the lives of 20,000 adults in South Yorkshire over the next 10 years see <http://clahrc-sy.nihr.ac.uk/south-yorkshire-cohort.html>

User involvement

This proposal was developed and conducted by members of the Obesity theme of NIHR CLAHRC SY in collaboration with the NIHR CLAHRC SY stroke theme and representatives from health, voluntary sector and lay groups.

This project has been developed in response to discussion at a series of coproduction, research prioritisation events involving staff from NHS, local authority, academic and voluntary and community sectors from across South Yorkshire. Here issues were identified that would benefit from exploratory research to develop insight and inform future practices and pathways.

Stroke specialist clinical staff and academics were on an advisory group for the research study. The advisory group provided on-going advice regarding the study design, patient recruitment, study documents, analysis and dissemination.

Chapter 2: Study aim and research question

Study Aim

The study aimed to explore the rehabilitation and weight management experiences of stroke survivors of working age (<70) within the South Yorkshire locality in order to:

- Identify whether weight gain is a problem for some people following a stroke.
- Identify what factors contribute to weight gain.
- Identify appropriate and accessible interventions to prevent weight gain.
- Develop data collection tools for a larger study if required.

Objectives:

- Secondary analysis of the SYC data to explore weight gain prevalence and patterns in people following a stroke (Phase 1)
- Conduct a survey to identify health and lifestyle changes in SYC participants following a stroke and access to post stroke services (Phase 1)
- Conduct interviews with participants and staff to generate in depth understanding of factors influencing weight gain (Phase 2)

Research Questions:

- What are the experiences of weight gain in stroke survivors of younger age and what are the related weight management information and support needs?
- Do current stroke rehabilitation pathway and weight loss/management services provide weight management interventions and information that meet the needs of stroke patients and are accessible to them?

Chapter 3: Methods

Study Design

The study used a mixed method design and included a survey, face to face in-depth interviews and framework analysis methods. The triangulation of the survey and interview data added to the rigour of the findings.

Sample, identification and recruitment

Phase 1 - survey

A population based survey was conducted with participants of the South Yorkshire Cohort (SYC). The cohort includes people who live across South Yorkshire and Derbyshire. The SYC has been granted NHS Research Ethics Committee permissions for the cohort to be used for additional research. For this study, participants of the SYC who consented to be contacted again to take part in future research, were under 70 years of age and had reported having had a stroke were sent the survey (n=193, May 2013). It was not clear from the existing SYC data when the respondent's stroke had occurred or whether the person would still be receiving support under the 12 week pathway of care. It was also unclear whether people were overweight or obese before or after the stroke.

Phase 2 - patient interviews

Semi-structured interviews took place with overweight (BMI = >25) patients who have had a stroke (n=12), and who live in Sheffield. Participants were survey respondents in phase 1 who indicated in their survey response they were interested in the interview participation (n=10) and a participants of a stroke community support group run by stroke survivors (n=2). Purposive sampling (Bowling, 1997; Field & Morse, 1985) was used to ensure the appropriate range of relevant characteristics i.e. age, gender, weight, location, time since their stroke, marital status, socio-economic and work history.

Inclusion criteria for the patient sample included:

- Male / female who have had a stroke
- Living in Sheffield
- Between 18 and 70 years of age
- Able to speak English
- Able to speak (Aphasia friendly)
- Self-reported BMI >25

Table 1- Characteristics of Patients Interviewed

Participant Number	Sex	Age range (years)	Date of First stroke	Weight Change
1	M	50 - 59	2011	Increase 4 stone
2	M	40 - 49	2010	Increase
3	F	30 - 39	2006	Increase 6lbs
4	M	60 - 69	2004	Decrease 22lbs
5	M	70 +	2000	Increase 9lbs
6	F	60 - 69	2010	Decrease 1 stone
7	F	50 - 59	2005	Decrease 1 stone
8	F	50 -59	2007	Increase 10 lbs
9	M	50 - 59	2009	Increase 12lbs
10	F	60 - 69	2001	Increase 21lbs
11	F	60 - 69	2009	Decrease 8lbs
12	F	40 - 49	2010	Decrease 1 stone

Phase 2 - staff interviews

Interviews explored staff perceptions of increases in weight following a stroke and the acceptability and accessibility of services for these patients. Staff and service providers were recruited for interview (n=18). Staff who worked in front line and strategic roles from a variety of health and social care organisations in the voluntary, statutory and community sectors and regularly come in to contact with stroke patients or commission stroke services were contacted by email.

Purposive sampling was carried out following consultation with the project advisory group in order to incorporate staff from a range of services and perspectives.

Table 2 - staff participants

Role	Pathway
Clinical Psychologist	Strategic
Nurse Specialist	Strategic
Speech and Language Therapist	Strategic
Dietician	Acute
Occupational Therapist	Acute
Stroke Consultant	Acute
Dietician	Intermediate Care
Occupational Therapist	Intermediate Care
Physiotherapist	Intermediate Care
Psychologist	Intermediate Care
Sister / Modern Matron	Intermediate Care
Speech and Language Therapist	Intermediate Care
Dietician	Community
Occupational Therapist	Community
Physiotherapist	Community
Stroke Nurse	Community
Sister / Modern Matron	Long Term Rehab
Re-ablement Coordinator	Voluntary Sector

Data analysis

Survey data was analysed using SPSS to generate descriptions of the sample and identify potential relationships between variables.

Interview data was transcribed, anonymised and entered onto password protected computers in Microsoft Office Word. Framework Analysis (Ritchie and Lewis, 2003) methods were used to analyse the data. Framework Analysis involves a systematic process of sifting, charting and sorting the material into key issues and themes allowing the integration of pre-existing themes into the emerging data analysis. NVIVO version 10 was used to store and manage the data.

Strengths and limitations

- The triangulated approach added breadth and rigour to the findings.
- The survey was posted over the summer of 2013 with a covering letter related to the study and a letter from the SYC project manager. SYC, CLAHRC SY and Sheffield Hallam University identifying logos and a unique participant identifier number was included on the survey which linked to the SYC database there a track of who has responded could be provided to the SYC trials team.
- There may have been responder bias in the survey i.e. those who have gained most weight or for which weight isn't a problem may not have responded.

- The sample size was relatively small; although some differences were identified a larger prospective study may strengthen this.
- The study used a pragmatic design but recruited retrospectively, future studies would benefit from a prospective cohort study.
- The study was conducted in one location and would benefit from being expanded to look at other locations.

Chapter 4: Results

4.1 Survey

A copy of the survey can be seen in appendix A. 193 surveys were sent out, 88 responses were received (response rate = 45%). A summary of responses to each question are presented below. Some questions were not fully completed by every participant.



Age at first stroke: Range 22years - 68years, Mean age 53 years

61 people had 1 stroke

22 people had more than 1 stroke (range 2-7 stroke)

Before Stroke (mean)

After Stroke (mean)

Weight 176lb

Weight 181lb

Participants weight before a stroke ranged from 119lb to 252lb whilst after experiencing a stroke their weight ranged from 125lb to 341lb.

There was an increase in weight following a stroke. (P=0.29, difference 5.54lbs, 95% confidence intervals - 0.6lbs - 10.51lbs)

Chart 1 Problems following their stroke

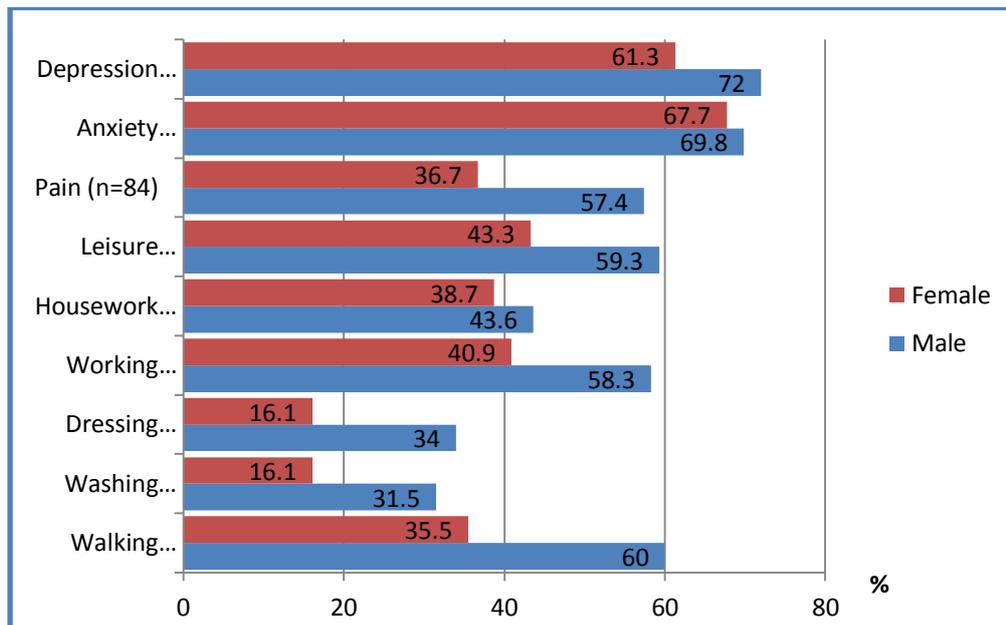


Chart 1 demonstrates the difference in reported problems following a stroke between men and women. Men report more problems with walking. All other reported problems are higher for men but are not statistically significant.

Employment

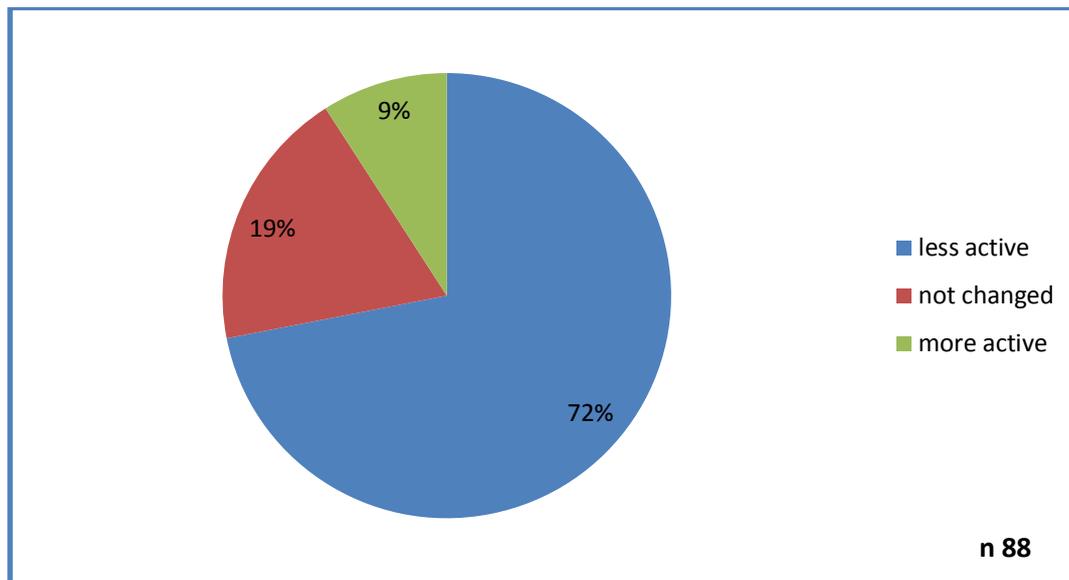
- Working (full time, part time, paid or unpaid, a carer or housewife/husband) before stroke n=65
- Working now n=29
- Not working due to stroke n=24

The proportion of men and women working prior to having a stroke is broken down fairly evenly with 75% of men in work and 73% of women.

Asking about employment now there is a marked difference with only 26% of men working now and 50% of women working now.

When participants were asked if they are not working now as a result of their stroke 54% of men stated that they were compared to 21% of women.

Chart 2 - Level of activity after stroke

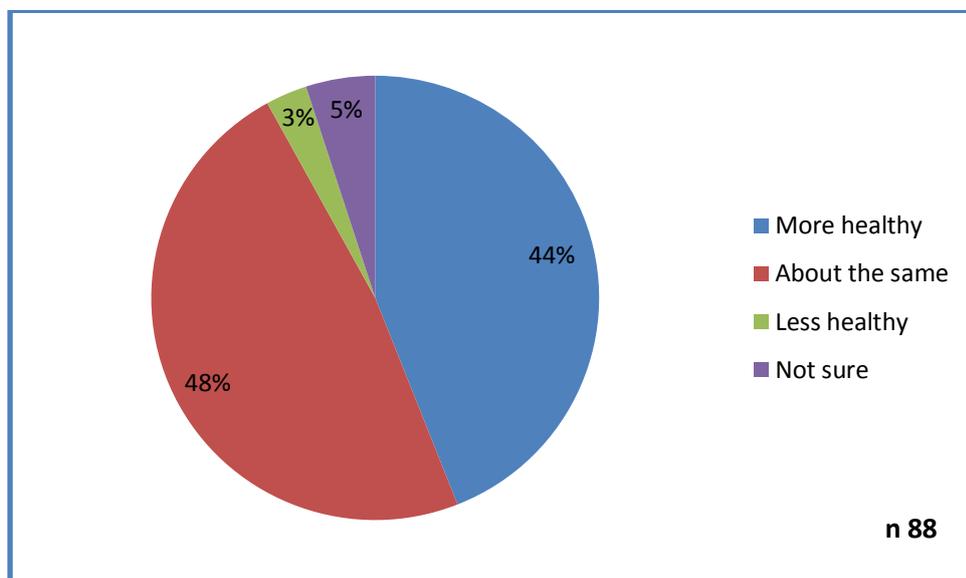


Nearly three quarters of the respondents reported being less active following their stroke. Reasons why activity levels have changed following stroke included:

- *“Feelings of fatigue”* (Participant ID 61)
- *“Difficulty walking and poor balance”* (Participant ID 60)
- *“Try to exercise more by walking more – 2-3 miles a couple of times per week. I have also take up gardening”* (Participant ID 6)
- *“Lack of interest in any activities”* (Participant ID 13)
- *“Retired, more time available for walking, gardening and other activities”* (Participant ID 86)
- *“Sadness”* (Participant ID 46)
- *“Unfortunately my stroke was caused by too much physical exercise in the gym”* (Participant ID 9)

Of those who had reported that their weight had increased since their stroke, 47% said they were less active. No participants who reported being more active since their stroke has put on weight compared to 0% of respondents who were more active. Those who increased their activity levels were highly likely to lose weight.

Chart 3- Diet following stroke

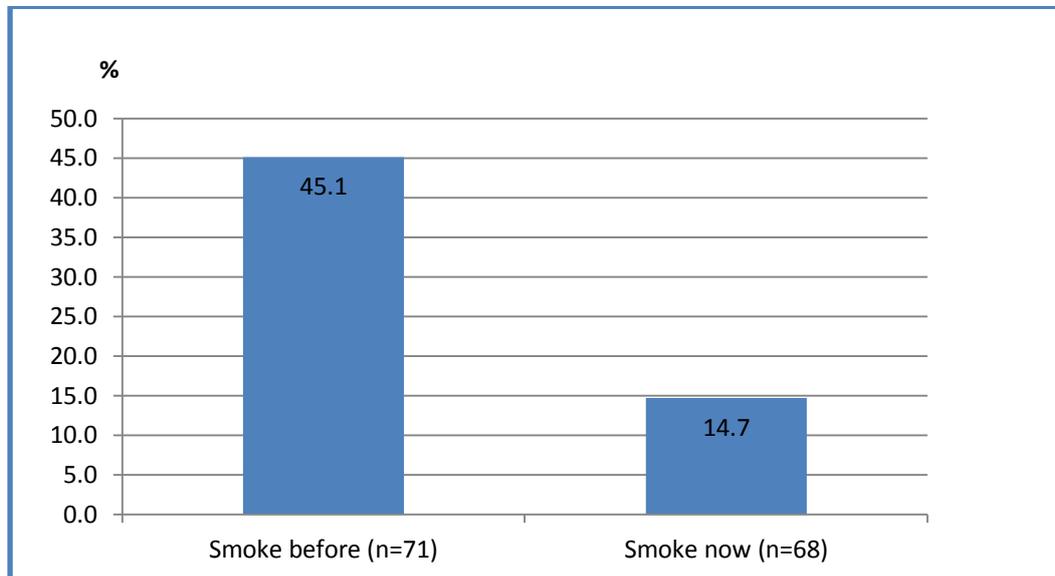


Nearly half reported their diet as being more healthy and half as about the same following their stroke. Reasons why respondents thought their diets has changed following stroke included:

- *“Being less active I know I should eat less, plus I do try to limit some foods I know are not healthy”* (Participant ID20)
- *“Can’t be bothered to cook. I live on my own no help”* (Participant ID 25)
- *“Cutting out salt, sugar. Eating more veg, fruit and fibre”* (Participant ID 71)
- *“Direction of spouse!”* (Participant ID 51)
- *“Do not want to put on weight”* (Participant ID 29)
- *“I always had a healthy diet before my stroke”* (Participant ID 62)
- *“I eat a lot more healthy, or I try to”* (Participant ID 31)

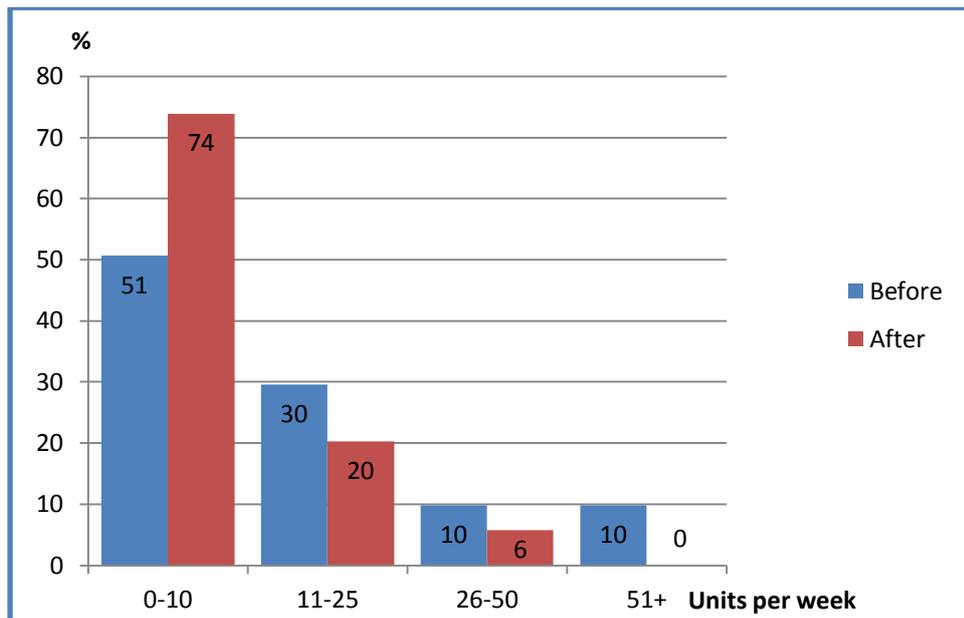
Of those whose diets are the same or more healthy there was no difference in weight.

Chart 4 - Smoking - before and after stroke



The chart above demonstrates that a third of those who smoked prior to their stroke continued to smoke after their stroke. For those still smoking, the reported numbers of cigarettes smoked each day reduced after the stroke. The rate of smoking prior to the stroke ranged between 5 - 40 cigarettes per day and changed to between 3-20 cigarettes a day after the stroke. In this sample those who stopped smoking since their stroke were more likely to have gained weight since their stroke.

Chart 5 - Units of alcohol before and after stroke



No participant reported drinking more alcohol following their stroke and overall alcohol consumption reduced. Reported reasons for this reduction included:

- *“Alcohol not compatible with medication”* (Participant ID 84)
- *“Concerted effort to cut down but found this difficult”* (Participant ID 87)
- *“Cost”* (Participant ID 64)
- *“Do not drink at all now”* (Participant ID 28)
- *“Don’t go out as much”* (Participant ID 65, 73, 43)
- *“More selective, more aware”* (Participant ID 2)
- *“My social life has been reduced severely”* (Participant ID 62)
- *“You only have one life and I want to see my family and grandchildren grow up and a better life for me”* (Participant ID 57)

Those respondents who lost weight were more likely to drink less.

Questions were included to ask people where they got advice on diet and physical activity following their stroke. A considerable number of participants (n=30 diet, n=43 physical activity) did not answer or said no to every option on either question. It was assumed that this was because respondents had not received any information on diet and physical activity.

Chart 6 - Diet information from services

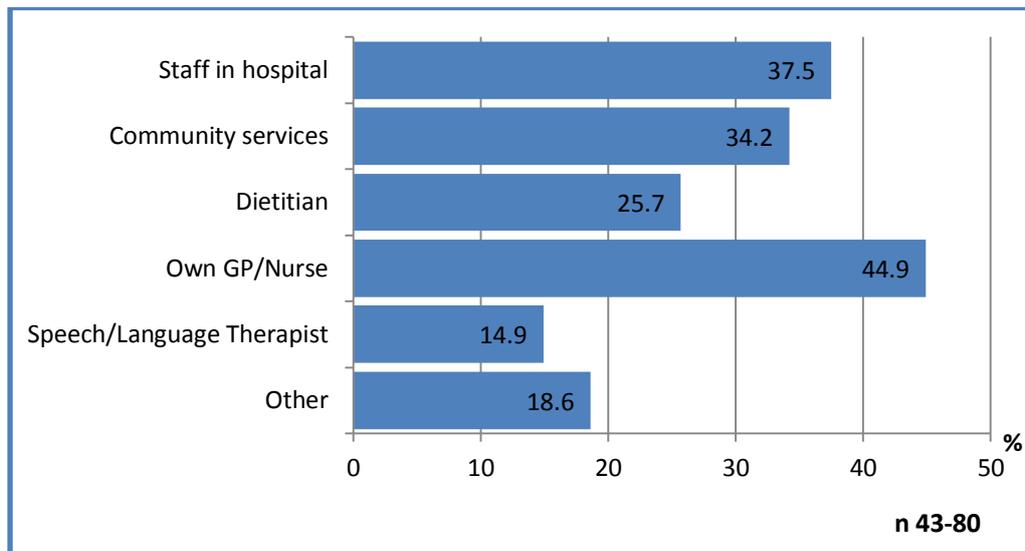
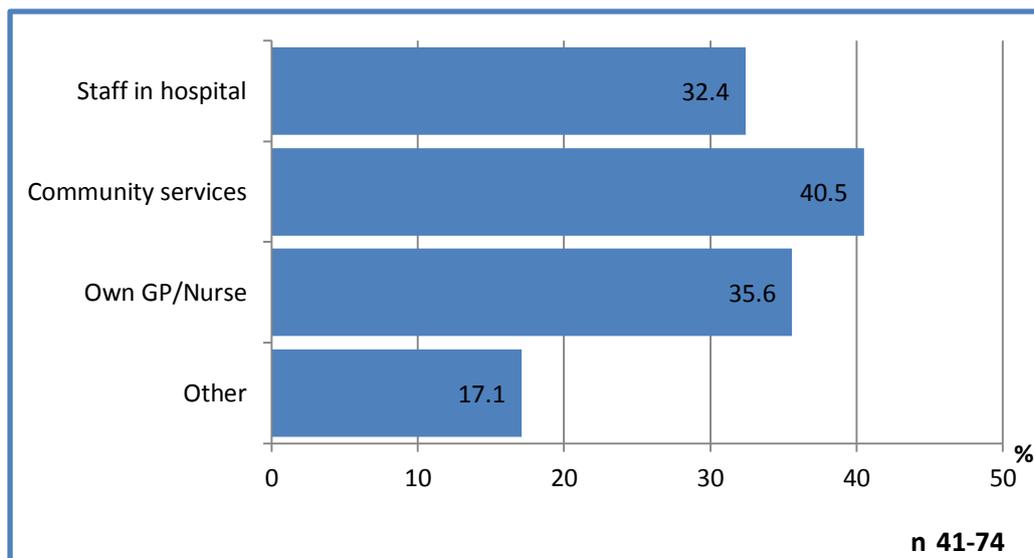


Chart 7 - Physical activity information from services



Other sources of information given by participants included:

- *“Following my stroke, after regaining use of my limbs I played a large part in the help of others affected by stroke. This put me in contact with various sources of information”* (Participant ID 62)
- *“Health services”* (Participant ID 46,55,67,71)
- *“Hospital gave me a big book, stroke handbook. Tells you all you need to know”* (Participant ID 35)
- *“Internet”* (Participant ID 2,9,20,21,27,29,33,72,73,77,82,85)
- *“Not on the internet as I cannot use computers etc. because of my stroke”* (Participant ID 14)
- *“Weightwatchers”* (Participant ID 56)

Case studies

The case studies below are summaries from two of the survey participants. Each example highlights the changes that can occur to someone's lifestyle following a stroke. Changes to diet and alcohol are evident; however like many more of the respondents the physiological consequences of the stroke make it difficult to increase physical activity levels. Case study two illustrates that a stroke can be attributed to too much exercise, which can compromise someone's ability to take up exercise again after the stroke.

Box 1, Case Study 1

Case study 1

- Male, aged 49 years
- 2 x strokes, First stroke in 2006, subsequent stroke date was not given
- Range of problems since stroke including:
 - Gained 7st 4lbs
 - Low mobility
 - Not working since stroke
 - Less active since stroke
- Diet is more healthy – attending sessions on healthy eating planning
- 200 units of alcohol per week before stroke. Doesn't drink alcohol now
- No support given on diet and exercise
- Self-directed information-internet, family, leaflets

Box 2, Case Study 2

Case study 2

- Male, aged 53 years
- Stroke in 2007
- No problems with activity, but feels depressed and anxious
- Weight loss 1 stone 1lb
- Diet is healthier. He has cut out biscuits, cakes, chocolate
- Not working now, unrelated to the stroke
- Less active – stroke caused by too much activity in the gym
- Diet more healthy – checking food and looking out for less saturated fat, sugar and salt
- 20 units of alcohol before stroke, 6 now
- No support given on diet and exercise
- Self-directed information – internet, newspapers and supermarkets

3.2 Patient Interviews

In the following section findings are provided in relation to the main themes emerging from the patient interview data.

Table 3 - patient interviews

Themes	Sub themes
Lifestyle	<ul style="list-style-type: none">• Weight• Pre-stroke• Post-stroke
Networks of support	<ul style="list-style-type: none">• New support• Health care support• Existing support
Impacts of the stroke	<ul style="list-style-type: none">• Physiological• Psychological• Assumptions
Health care	<ul style="list-style-type: none">• Straight talking• Navigating• Integrating• Closed door
Personal emotion	<ul style="list-style-type: none">• Treat me• I'm not old• Journey to acceptance• I'm a different person

Lifestyle

Changes to weight and lifestyle pre and post stroke were identified in the data. Some participants reported that their weight gradually increased after their stroke, whereas others talked about losing weight immediately after their stroke. Participants had made lifestyle changes which had impacted on weight loss or weight gain.

Weight: The findings from the twelve patient interviews did not provide a consistent picture of weight gain or loss. Participants were able to say quite precisely the levels of weight change that has occurred after their stroke. This varied between losing weight immediately after the stroke and gaining weight during recovery.

"I'd lost, when I initially, when I came out of hospital I'd lost at least two stone in weight" (Patient P6)

"I've put on around four stone, a fair amount of weight really" (Patient P1)

Participants were also able to talk about their weight and lifestyle at the time they had their stroke and how their weight was influenced by changes in lifestyle brought about by other illnesses.

"I was heavier when I had my stroke, but I have lost weight, I was about 19 stone, but the weight I've lost is not because of the stroke. I have other bladder problems" (Patient P12).

Clear examples were given of lifestyle changes participants had made following their stroke that had contributed to weight gain. Participants who stopped smoking discussed the links with weight gain and how smoking was often replaced with eating:

"For me personally I stopped smoking. Now when you're on 20 cigars a day right okay, that's quite a big loss of something you used to do so you have to replace that..... But I think I replaced it with biscuits, cakes and eating." (Patient P1)

Those who had active lives prior to their stroke talked about filling their time, with eating.

"I would say sheer boredom. All of a sudden you've got all this time on your hands and you worry and you comfort eat" (Patient P2).

Lifestyle pre-stroke: Health and lifestyle before the stroke was discussed. Some participants reported they were fit and active before their stroke, and some were very active. Others talked about diet and the lengths that they went to, to eat healthily

"So I would think I was in reasonable health, not a marathon runner but in reasonable health, you know. I did smoke, so that might have contributed. But I wasn't taking any statins or anything else for other ailments" (Patient P1).

"I was always one of those people that would get up at half past six every morning regardless. You know, get up, go swimming, go to work, do a full day at work, come home, be doing things. So yeah I was always quite active" (Patient P3).

"I'm fit, healthy. I'm very conscious of my diet, I'm vegetarian, I grow my own veg" (Patient P7).

Lifestyle post-stroke: Participants explained how the stroke has impacted on their lifestyles. Diets, activity levels, alcohol intake and social lives were all affected by the stroke:

"I knew I had a shift in diets because if I were hungry when I were at work I'd just get a Mars Bar or something like that to suffice, a sugar rush or something like that, but now I prefer savoury things to sweet things" (Patient P2)

"I'd say that the social aspect of life was probably the most hit, because I just couldn't be bothered to do anything. I think that being at work during the day was so draining and tiring that when I came home at night I just didn't really fancy doing anything at all" (Patient P3)

"I've cleaned my life up even more because I was a moderate drinker.....It ruined my social life when I stopped drinking but that's another issue" (Patient P7)

One patient who noticed they were gaining weight and losing fitness and strength after his stroke spoke specifically about being encouraged to increase his physical activity levels by going to a gym.

"I was very fortunate I was referred to a gym, but it was during that point then you start realising then that actually this, if I don't do something I'm going to lose everything" (Patient P1).

Networks of support

Existing support: Support from wives, husbands and a family was considered to be crucial in recovery. The encouragement and support they provided helped to restore normal activities of living.

"Wives and carers need to be 100% involved in what's going on..... they need to be involved because it's them that's dealing with it 24/7 hours a day" (Patient P2).

"he doesn't always do for me, you know, he lets me do things and, you know. And I'm grateful for that, because it would be very easy just to sit and let him make me a cup of tea or whatever and, but it's not good for you"(Patient P6).

Responsibilities of caring for other family members and pets helped provide the motivation to be active and recover from the stroke.

"And my dog helped..... he's got me going. I've had to get out and do for him." (Patient P6).

Health care support: Patients spoke about a lack of support and information from health services and professionals to help them change their lifestyle after their stroke. This was especially apparent where patients were perceived by health care professionals to be healthy, slim or follow a healthy diet:

"I got no help. I didn't even get a leaflet in hospital or anything like that." (Patient P12).

"I happened to look like the healthiest person they'd had through in a long time. And that got commented on almost every time, oh you're too young to be here, you're too healthy to have had a stroke you know and it's almost like well they gave me, the stroke nurse when she took my history she handed me these A4 papers and then almost pulled them back and handed them me again saying oh you don't really need any of this advice." (Patient P7)

However others commented on their readiness to receive the information on lifestyle and health. They notes that if the timing of information was wrong and people weren't ready or willing to accept information the health care practitioner was wasting their time.

"They probably thought they were flogging a dead horse. I think it were all right, I think diet and that were discussed, but I'm stubborn and I probably wouldn't have taken any notice of diet anyways." (Patient P9)

New support: A participant involved with setting up a local volunteer led stroke group specifically mentioned the lack of support for younger stroke survivors.

"There's nothing in Sheffield, was nothing in Sheffield. They're all like bingo groups, so catering for your older age ladies and gentlemen, sat there playing bingo and one thing or another." (Patient P2).

Feedback about the support provided by this voluntary group was positive as it allowed stroke survivors the opportunity to feel at ease and have fun with others who had suffered from a similar event.

"They're laughing and joking about stupid things, and everybody is the same. Everybody is happy and that's all it takes, a little bit of laughter and a bit of support, and it goes a long way. It really does, that is a lot of the time all that people want." (Patient P2).

".....and Different Strokes are smashing, they really are" (Patient P7)

Voluntary-led support groups can offer long term provision for patients which is something that the NHS did not appear to provide for the stroke survivors in this study. Support groups provided the opportunity to have open communications with other stroke patients to share their experiences rather than learning from literature was important:

"Having open forums where you can go and sit down and talk to people about things, who have lived through it rather than people that have learned about it from a book, makes a lot of difference" (Patient P3)

Impacts of the stroke

Physiological impacts: The extent and type of impacts the stroke had on this sample varied between individuals, as did and the time taken to recover. Participants gave examples of how the physiological effects of the stroke impacted in different ways, ranging from mobility, to vision and balance.

"I couldn't walk around outside really, you know. I couldn't, I could get to really to the gate but I wasn't confident enough about walking over the road or anything like that" (Patient P4)

"I lost a lot of my vision. I've got a guide dog; he's in kitchen at the moment. A lot of my left hand side were weak, balance and everything had gone" (Patient P2).

The rate at which the participants recovered from the physiological effects of the stroke varied. Tiredness was something that was reported in a number of interviews:

"But everything else seems to be I've hit that sort of plateau and I think now I can, not exactly concentrate on things, no I suppose it is that, I probably can think well lets address other issues, maybe, you know, the tiredness I guess" (Patient P8)

"My walking is, well I can walk up to about two miles now. I walk with the dog and that's about my maximum, is just two miles and that takes me quite a long time, but I do it. But as I get tired my leg gets more, I find my foot drags more, it drops a bit" (Patient P6)

The physiological impacts of the stroke caused both limited mobility and movement and changes in cognition. All of these could impact on weight gain.

Psychological: Mild cognitive impairment impacted on awareness of food consumption, appetite and ultimately weight gain.

"the memory's not there anymore, how have I put all this weight on? I've not eaten anything, been different, to what I normally eat apart from, four a day doesn't mean four packets of bloomin' biscuits a day" (Patient P7)

Loss of memory frustrated participants and embarrassed them in front of their friends and families:

"Yeah, my memory is absolutely appalling. I went to shop for one thing and I come back, what did I come down for? And I buy all sorts of crap, and I'll come back and she'll say did you get bread? Oh hell, back down the shop for some bread, the one thing that I went for that I just totally forgot about it." (Patient P2)

The stroke also triggered strong emotions. Distress and avoidance of certain situations became normal. Whilst this improved for some during the recovery process, other participants talked about having to learn to be in the company of others again, limiting their social activity:

"Initially I found I was very emotional in certain situations. I'm a lot better with that now, but certainly my brain gets tired. I don't like rooms with a lot of people in; the noise is too much for me sometimes. But I cope. I perhaps possibly don't put myself in the situations that I would find difficult if I can avoid them." (Patient P9)

Health care

Straight talking: Participants thought that medical staff did not always give them enough detail and information about their stroke and potential rate of recovery. They requested that health practitioners were more honest and realistic about the time and extent of recovery possible:

"I do feel that when it first happened, when I first went to the stroke assessment clinic, I think at that point it would have been a lot nicer for someone to sit down properly and explain what was going on and why it might have happened, which I think is the one thing that was lacking at the time, of someone just having half-an-hour explaining it properly" (Patient, P3).

"I think they ought to be able to talk to the patients more about how it might affect them mentally" (Patient P8).

Furthermore, the ways in which health staff communicated with patients was considered important. It was necessary to speak in a language that patients can understand and refraining from using medical terminology. This helped participants to process and understand what had happened and what was happening to them:

"He was just straight. He spoke to me on my level, rather than trying to be medical about everything" (Patient P9)

"He [consultant] sat me down and explained everything to me so I wouldn't get frightened again" (Patient 12)

Navigating: Participants reported problems navigating NHS services and stroke support. One patient's family had to seek additional support. This meant they then went from receiving little help to being overwhelmed with the number of people and organisations that got involved:

"my wife went down to the doctors and said, look, my husband had a stroke seven week ago, nobody has been round to house and things are getting really bad, to the point of despair. So he got in contact with, it were the CICS team then. I can't remember what they were called, anyway the physio teams around Sheffield, and then they started coming, the physio team, the occupation therapy and then the Royal Society of Blind..... So all of sudden from nothing, you've got hundreds of people just coming all at once, and that's a hard thing to try and deal with. Your house is your own and then it's not" (Patient, P2)

Closed door: At the time the participants had their stroke patients were supported by the community stroke team for 12 weeks. After this they were discharged, referred back to their GP or onto further stroke services if clinically appropriate. For those participants who weren't referred for further support this was a worrying time and patients reported feeling isolated and unsure where to turn for further support:

"We've done what we can (referring to Community Stroke Team)....that's all we can do for you now....I'm thinking what happens next? Is it down to me? is there something out there? but there is nothing out there" (Patient P1).

Personal emotion

Treat me: Being treated as an individual was important to the participants in their recovery process. Setting personal goals that would aid rehabilitation and re-assemble their previous life was considered valuable. Personal goals were perceived more important than some service goals that seemed like a tick box exercise to enable services to discharge them:

"I didn't feel that I was look [looked] at as an individual.....There was the thing in the kitchen, could I make a cup of tea by myself. Yeah okay I can do that. I didn't pour water over my hand or anything else like that I was able to do that brilliant. So I was safe and I get that part of it.....You know, I am this age, I want to be getting to there, how are you going to help me get to that point, what can I do that's going to make that, what can I do now that's going to get me up there. And there was none of that really. There was nothing that really helped that they did that was really going to help me, other than routine". (Patient P1)

I'm not old: Age was a theme to emerge from across all the interviews. From the acute setting through to community based services, participants referred to experiences where they had felt they were treated like an old person, not someone of working age. In the acute setting many patients around them were old, and they felt out of place.

"I were put with a load of old age people, and no disrespect to anybody that's of the older years, I couldn't get any rest because there were buzzers going off all the time" (Patient P2).

"You've got people on same ward, like 65, 70-year-old, fair enough, things happen, but at 45 it's like hang on a minute, I shouldn't be here" (Patient P9).

Out-patients services were also considered to be set up for the elderly population, rather than younger people who had experienced a stroke:

"The health, because you had to keep going back down to [Name of Hospital] Hospital and where do you go? You go into the elderly care centre, which is not very nice to go in there, and you sit down and you look around. All sit around and you find yourself surrounded by old, old people, and I'm not being nasty to them, well I hope I'm not, you know, I just didn't feel like I was in the right place" (Patient P1)

Community services didn't always consider the needs of younger people who wanted to go out with their families:

"And I sort of said look, I'm a young person, I've got young children, I mean I've got things to do. And I was still trying to do them. I felt that you get treated like a 70-year-old who's had a stroke. And obviously I know that young people, under a certain age, under 70 is a very

small minority, most people are over 70 and you just felt like this is the way they treat then, you know, you're an old person you'll be sat at home doing nothing, but actually no I've got things I want to do. I still want to go shopping, I still want to go and visit people, I still want to get back into work and things, so I was trying to do things and, you know, I'm just not on their beck and call here, you know, it's not as easy as that" (Patient, P1).

Journey to acceptance: Accepting the stroke has occurred and the physiological, psychological and emotional impacts takes time and was very much an individual process. Some participants were quite blunt about how they had to accept what had happened.

"You know, well it is, you live with it, well you've got no bloody option really have you?" (Patient P4).

Clear examples of the journey to acceptance were given. The quotes in the case study 3 below from participant 2 demonstrate this:

Box 3, Case Study 3

Immediately after the stroke "Was I quite poorly? I don't think I were. My wife would disagree, and I suppose everybody else would disagree. Dealing with it within my head, I'm a very, am I still an alpha male? Yes, I am. I was a very alpha male, so as far as pride and everything else that went with it, it messed about with my head big style, it really did."

Fighting back "it's that battle of wills within yourself; it's that, that's hard. For me personally, I can't speak for anybody else, but what don't make you will break you, and it made me, it didn't break me so I'm lucky on that aspect.

Reflections and the future "The hardest part of that 1,000 mile journey is a first step because it's not 1,000 miles anymore, and each and every step that you make after that it gets closer, and it gets easier, but the hardest step is the first step. And after that you want it more, so you get more hungry or the pace starts getting faster and faster, yeah, definitely.

There were many examples of people fighting to get on with things and with internal motivation to improve. Some participants reflected that their stroke could have been much worse and they had got away lightly compared to others that they know.

"But I think some people lose their drive to do things. And I'm maybe lucky that I've, from the very first day that, when I knew I'd managed a night and I was still alive, with my heart and the stroke I was determined I was going to make the best of it I could do and I've stuck with that really all the way. It's hard, it's very hard" (Patient P6).

I'm a different person: Participants discussed changes to their physical and psychological self. Their ability to work and care for others and provide for the family, had changed. Some now had to rely on others to eat, dress and socialise. This meant that participants felt that they were a different person

as a result of their stroke. In some cases this was judged to be for the better as the recovery had provided a time to reflect and readdress where their life was heading. In other circumstances participants found it harder to accept the differences. This not only meant that they themselves needed to learn who they were and what they could do but also that their family and friends had to deal with the changes and this 'new person':

"So everything in your life is suddenly changed and it's almost like you've been off, sort of tilted of centre and. You're still running your life, you're still trying to do your life, but you're just suddenly you're not able to do the things you could do. And it's simple things, you know, your writing's affected, your speech is affected. If you're trying to do your normal routine stuff, you know, banking and talking to people on the telephone, it's all affected by it"
(Patient, P1)

In summary the patient interviews build on insight generated from the survey revealed that some people did struggle with weight gain following their stroke. Experience of weight varied following the stroke and some gained weight. Stopping smoking, boredom, reduced activity and the psychological impact of the stroke contributed to weight gain. For those who gained weight the stroke increased social isolation and impacted on other health behaviours e.g. alcohol consumption. The nature and timing of information to prevent weight loss and maintain a healthy weight varied across participants.

3.3 Staff Interviews

In the following section findings are provided in relation to the main themes emerging from the staff interview data.

Table 4 - Staff Interviews

Themes	Sub themes
Control	<ul style="list-style-type: none"> • Loss <ul style="list-style-type: none"> ○ Physical impairment ○ Communication ○ Cognition • Socio-economic status
Support	<ul style="list-style-type: none"> • Communication <ul style="list-style-type: none"> ○ Intra professional organisational uncertainty ○ HCP responsibility ○ Conflict • Gaps in knowledge <ul style="list-style-type: none"> ○ Monitoring of weight gain ○ Knowledge of patients ○ Knowledge of HCP and wider services • Type of information <ul style="list-style-type: none"> ○ Health promotion advice for patient and family ○ Bespoke approach • Services <ul style="list-style-type: none"> ○ Voluntary sector ○ Stroke care pathway and transition ○ Service cuts ○ Access
Weight gain	<ul style="list-style-type: none"> • Impact • Influence <ul style="list-style-type: none"> ○ Food providers ○ Social isolation ○ Psychological effects ○ Physiological effects ○ Lifestyle before stroke ○ Age • Prevalence <ul style="list-style-type: none"> ○ Weight loss ○ Timing of onset ○ Does exist

Control

Staff described the loss of control people have following a stroke. The physical impairments and problems with communication and cognition all have major impacts on the extent of recovery and time taken for patients to recover. The extent to this loss of control is far-reaching and staff viewed it as a critical influence on the potential for future weight gain.

Physical impairment: The impact of changes in physical ability following a stroke was considerable. Loss of mobility and vision led to social isolation. Even in the home patients may well need to adapt their environment or have aids to help them get around. Staff reported that patients who lose control over aspects of their lives take time to accept this, especially in those people who were not chronically ill prior to their stroke. The combination of loss of control, mobility and physical impairment was thought to be an influencing factor on weight gain.

"They've lost their independence; they've lost the freedom to go out. Most of these people were able-bodied beforehand and have become suddenly very disabled, so they've got to come to terms with their new disability" (Staff, P1)

"For the majority of people if they haven't got any disabling illnesses before it comes as a big shock having a stroke. I mean for working age people it stops you driving, you're not allowed to drive, your environment, your home environment may need changing, you may become incontinent, you're not able to walk about" (Staff, P4)

Communication: In relation to eating and drinking, losing the ability to communicate with friends, family and carers was considered to have a long term impact on weight gain. Staff highlighted issues in those patients who can't express to others what they want to eat, therefore having to rely on food being provided.

"She wasn't able to express clearly as well around what she wanted to eat actually, so those decisions were made by family or carers" (Staff, P2).

Cognition: Like the patient interviewees, the staff reported how cognitive impairments can further influence the chances of gaining weight. For example through losing the ability to control portion sizes, decide what foods to have or whether to take exercise, and the increased reliance on others as food providers:

"Stroke affects appetite, so you can actually get, because of the brain damage in certain areas of the brain, can cause, it's a bit like losing inhibitions. You lose the ability to decide what's the right quantities, so it requires somebody else to decide for you" (Staff. P1)

Staff also reported that patients were not always aware that they were increasing their weight. Examples were given of people whose lifestyle changed due to cognitive impairment and because of this were gaining weight:

"I can think of one patient where that has been an issue, where the portion sizes haven't changed in relation to the level of physical output, so she did end up putting on weight. She had cognitive impairment so it meant that she wasn't in a position to take on board and rationalise and manipulate the information to be able to understand and express a wish to have smaller portions, even though she was aware she was putting on weight. (Staff, P2)

Participants suggested that for those patients where cognitive impairment severely restricts lifestyle change, there is no real point trying to encourage patients to change.

"..plenty of patients where it's impossible to expect lifestyle change if there's significant cognitive impairment" (Staff, P14).

Socio-economic status: Staff participants described how socio-economic status was linked to stroke. This was both as a causal factor of poor lifestyles prior to the stroke and also by hindering the chance of engaging in positive lifestyle choices following a stroke:

"Where strokes tend to happen, if you look at some of the areas of Sheffield where we're looking at the poor socioeconomic areas, where making healthy choices is not something people have been doing anyway..... But certainly in some areas you get a lot more of the younger strokes that are overweight already, that tend to carry on with their unhealthy lifestyles. And that's part of almost a community thing" (Staff, P1)

Changing behaviours was considered more difficult by staff when patients lived in areas of increased deprivation, where income and access to quality food was low:

"Those innocent veg pots, they seem quite good. Yeah, I suppose they're better than having fat, but a lot of people can't afford. Yeah, they're much dearer. The things, they're a lot more expensive and a lot of people go perhaps to Iceland or things and the fat content in things is really high" (Staff, P5)

Support

Health Care Professional (HCP) responsibility: There was evidence of conflict between staff groups regarding the times at which patients should be given lifestyle information. Some thought it should start early in acute settings. However staff in the acute settings reported that they lacked the skills and time required.

"well I think that [health promotion advice] starts very early after a stroke. I think that possibly starts when people are still in hospital" (Staff, P10).

"In an acute setting I don't think it's necessarily our role to give them health promotion advice" (Staff, P9)

"I guess I don't need to have an in depth understanding of the pathway. I just need to deal with the patients on my ward" (Staff P9).

As a result of the relatively short (12 week) stroke pathway, services provided by the voluntary sector or those commissioned outside of the NHS could provide a vital support and rehabilitation opportunity to stroke patients. However staff were reluctant to refer to organisations and services outside of the NHS for fear of any comeback:

"It wouldn't be within our remit to direct the person to an individual thing. Other than general advice, you know, we might all give, but we wouldn't specifically refer them to another service without going back through the GP" (Staff, P6)

"We are all pushed to encourage people to think about voluntary sector and all that, but when it comes to it I don't think the majority of staff don't, partly because, this is going to sound awful, partly because, if we lead somebody down that route and they get involved in something, we almost hold responsibility for it" (Staff, P13)

Monitoring of weight gain: Staff participants were unclear about the extent to which weight gain was an issue for patients after a stroke. Weight was not routinely monitored across all departments, nor was it monitored long term. Various practical issues related to weighing patients in the community, and with patients with limited mobility were highlighted. However some staff participants were clear that weight gain was an issue with many patients, especially those that they come into contact with patients one to two years following their stroke. Participants said there was limited access to specialist services to refer to if they do highlight an concern about a patient's weight:

"We didn't really do BMIs on everybody until fairly recently in the last year or two, there is more that culture. And I systematically now whenever I see patients in clinic will send out a fact sheet on healthy eating; I will be more proactive in referring for dietetic support, even though there isn't an awful lot there in the community, there's always a waiting list and that, and then to focus a lot more on lifestyle" (Staff, P5)

Type of information

Health promotion advice for patient and family: Many staff offered health promotion advice to their patients but they were not always confident of how this would impact on behaviour change. Even where patients took part in practical physical activity sessions staff were not confident patients maintained this:

"I'll leave brochures and leaflets and smoking cessation stuff with them, knowing full well they're not going to do anything with it. But at least I can, I suppose in a sense I can tick my box to say they've got the information. And some of it's about cognitive impairment, you know, so it isn't easy" (Staff, P1)

"The physical activity that we encourage here, and obviously we can only, again we can give people advice, but whether they follow what they've been told why they're here is another thing" (Staff, P4)

Staff spoke of different ways they give the information about weight, lifestyle and stopping smoking and examples were given of using pictures of blood vessels, poor diets and smoking.

"I developed a way of approaching it so it's not focussing on the weight; I focus it on the stroke, so talking about its good to have a healthy diet to think about reducing the risk of stroke" (Staff, P8)

Bespoke approach: The timing of lifestyle advice and the manner it is given to patients was considered to be crucial. HCP's stressed the individual nature of acceptance and how people respond differently to the stroke:

"Some patients will see this is the warning shot, this is it, I can't believe I've been doing that, I'm going to change my ways, I'm going to do what you say. Some patients will need to hear it again and again and again. Some patients won't change what they do, irrespective of how many times you tell them" (Staff, P17)

"I'll go back a bit later and say let me come back and talk to you at another time, because timing is critical very often, with all of these things. And lifestyle changes you need hit people at the right moment. So I may come back later and talk to them again about it" (Staff, P1)

Services

Stroke care pathway and transition: The timing and length of the pathway was a theme in many of the interviews. There was concern that the length of the care pathway had reduced in recent years.

"In the past we would have had people in for longer" (Staff, P9).

Staff were sad that the time frame that they had to support patients in their recovery was so short. They saw that patients were being discharged even when staff knew patients would benefit in the long term from more clinical input:

"In an ideal world I would like there to be, I mean you're going to probably hear this from everybody, a long term stroke team in Sheffield... where patients can be monitored over years really, and have access to services that can really, and I'm talking as an occupational therapist, that can really look at overall occupational balance and function, and lifestyle as a whole, because obviously weight fluctuation, weight gain is complex. I mean it would be great as well if there were more opportunities for people to be able to access alternative environments easily with support" (Staff, P2)

Access: Staff felt that access to dietetics, community based weight management or physical activity services was poor. Where services existed staff spoke about long waiting lists.

"There is a service for people who are very overweight, but that's very underfunded and people have to wait months and months to access that service. So even where people have a long established identified problem it's not fantastic" (Staff, P3).

Transport and physical access to community based services was problematic for stroke patients. They described how, even where community transport existed patients suffering from poor mobility and cognition found it difficult to navigate the transport booking systems. The capacity of staff to provide the additional support to help patients access services to help their recovery was limited. Home based services were much easier to organise.

"The people who really need our services are the ones that can't access it, or those services rather, because they can't get out and about. Smoking cessation do a home visiting service which is great, but for things like exercise and activity stuff....." (Staff, P1).

Service cuts: There was a general feeling of reductions in the scale of community based schemes which promote exercise and physical activity:

"Sheffield used to be quite well set up in that people could easily access gyms and have, people that worked in the gyms could mentor them with a programme, and they were referred by their GPs and that sort of thing, but it seems to be a lot more problematic to access that sort of thing now" (Staff, P3)

Financial constraints and cuts to services were also thought to be increasingly problematic, particularly for those that are socially isolated

"There are less and less services. We used to rely heavily on luncheon clubs and respite care for the people that come in and have a period of time, none of that's available now" (Staff, P4)

Weight gain

Influence - Food providers: Following a stroke many patients cannot prepare their own meals and rely on family members, friends or carers to provide their food. Staff thought that this may influence whether a patient gains weight or not. Carers have little time to spend cooking fresh healthy food and rely on quick microwave meals which staff considered to be unhealthy, highly calorific and often laden with salt. Participants explained that some families have a limited understanding of healthy diets and portion sizes. 'Treats' to make stroke patients feel better were common place:

"when patients go out into the community, if they're not in a position to be independent with their meals and have control over shopping, which is the majority, then it is in the hands of either agencies or relatives. And what I've seen is relatives, I mean I think it's a way of

showing affection, it can be a way of showing affection, buying food that their relative who's had the stroke likes is one factor" (Staff, P2)

Social isolation: Stroke patients often become socially isolated because of the residual effects of the stroke. This impacted upon their diet, activity levels and vulnerability to weight gain:

"I saw a 48 year old, he hadn't got a very good social network, hadn't got a lot of support, big chap who was putting on weight all the time. He just couldn't prepare food, we couldn't get social services support enough for him, and it was just really difficult about how you could help him really without me going there every day and cooking for him" (Staff, P5)

Patients may spend much more of their day at home and often resort to food as a comfort.

"But they don't have anything in life, they're very lonely, they're isolated, so eating is the thing that keeps them going really. And it's difficult when I see those people to say well don't do that, because there is nothing else to replace that" (Staff, P1).

Psychological and physiological effects: Depression is strongly associated with stroke; staff participants in this study were able to give examples of how patients' mental health was affected. Impacts included using alcohol intake to make them feel better which may also impact on long term weight gain.

"In quite a number of cases increased their alcohol intake after the stroke because they've been fed up and depressed" (Staff, P5)

Along with changes to diets, reduced mobility and activity is a common consequence of strokes:

"Less activity, the vast majority of patients are spending a lot of time either in bed or sitting in a chair; they're not spending huge amounts of the day mobilising. They're the sort of patients that tend to put the weight on" (Staff, P3)

Weight gain was thought to be more apparent for those people who were more active prior to their stroke. Furthermore staff thought that people who were more active often continued to eat the same portion sizes which contributed to their weight gain.

"the people I see that I've noted gain weight have been the people who have been quite mobile prior, and then the stroke affected their mobility in some way" (Staff, P13).

Prevalence

Weight loss: Not all staff across the stroke pathway considered weight gain to be an issue for stroke patients. Those staff working at the acute end of the pathway were more focussed on weight loss, and rarely came across patients where weight gain was an issue to manage.

"we worry about people that are underweight, who are nutritionally malnourished" (Staff, P4)

“[weight gain] may become more of an issue later on but we don’t see it” (Staff, P7).

Whilst a few staff did not see weight gain as a concern the majority agreed that people following a stroke were vulnerable to weight gain. For those who did not recognise weight gain as a problem this may reflect the position at which they see a patient within the stroke care pathway. Staff described various physical and psychological impacts of the stroke which from their perspective can contribute to long term weight gain. They felt restricted in responding to information and support needs regarding weight management because of the constraints of the current time frames of the commissioned stroke pathway and the focus on the acute phase.

Chapter 5: Discussion

This study aimed to identify whether weight gain is a problem for some people following a stroke. The findings indicate this is so. The study also provides insight into the physical, psychological and social factors in some people following a stroke from the perspective of patients and staff. The current stroke service is restricted in its ability to deliver timely and individualised information, advice and support to prevent long term weight gain and promote weight management.

Key messages to emerge from the findings are now summarised followed by the main implications for practice.

Key messages:

Weight Gain

- The long-term effect of stroke on weight gain is a complex issue influenced by a range of pre-existing environmental factors and behaviours and the physiological and psychological effects of the stroke.
- Eating and activity behaviours and social isolation all play a part on weight gain, with the reduction in mobility and levels of activity being a key influence.
- Patients are challenged in controlling their diet following their stroke.
- Families and social networks influence weight gain.
- Long term follow up support would provide additional opportunities to influence the diets of patients and carers to reduce weight gain and risk factors for future chronic conditions.
- Social isolation and depression are a major factor in weight gain.
- Loss of control in cognition and communication impacts ability to manage diet and weight.
- Patients' socio-economic status impacts pre and post lifestyle choice.

Stroke pathway:

- The timing and type of health promotion advice needs to take a patient centred approach.
- The restriction of the pathway of support to the twelve weeks post stroke for most patients impacts the quality, appropriateness and acceptability of advice given to patients and carers.
- Care and information provided to stroke patients is restricted by pathways, availability of specialist support and current funding cuts to community based services.
- Fragmented communication between health care professionals across the pathway limits opportunities to address the risks and realities of weight gain.
- Ambiguity arises for patients because weight gain following a stroke can be both a sign of progress and of a problem.
- It remains unclear how common weight gain is as it is not a priority, monitored routinely or monitored long term.
- Knowledge and ability of wider support services hinders patients' recovery.
- Limited knowledge and availability of activity outside of NHS provision.
- Physiological impacts of stroke restrict possible engagement in community activity.
- Constrained knowledge of the whole stroke pathway - roles and responsibilities.
- Restricted support due to length of patient contact.

Implications for Practice

- The true extent of stroke related weight gain is unknown because services do not monitor or document weight across health care settings. Therefore a routine documentation of weight is required for people following a stroke as people move from acute, rehabilitation and survivorship phases of their care delivered in different settings.
- Health care professionals in different settings need to be mindful of the risk that people are susceptible to long term weight gain following stroke.
- Whether in acute, intermediate, rehab or primary care settings systems should be in place to identify opportunities for advice and support regarding diet and physical activity e.g. Making Every Contact Count (MECC).
- Information and support needs to be delivered in a timely manner and in an acceptable and accessible way to individual patients and their families.
- More work is required to ensure that messages regarding weight, diet and physical activity are consistent across settings.
- The study raises concerns regarding staff knowledge and awareness and the available systems to ensure referral occurs to weight management services.

Implications for research

- A large cohort study would provide population data to explore the prevalence and causes of weight gain following a stroke.
- The data collection tools developed in this study could be used in further research to explore the issue of weight gain.
- The current study was restricted in its patient sample selection for expediency it recruited from an existing cohort study. There would be merit in conducting a prospective longitudinal study mapping experiences of weight, diet and physical activity in people following people from patients from acute care to two years post stroke.

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Appendices

Appendix 1 - Survey

Sheffield Hallam University	Centre for Health and Social Care Research	For office use only <div style="border: 1px solid black; height: 40px; width: 150px;"></div>
CLAHRC for South Yorkshire	NHS National Institute for Health Research	

South Yorkshire Cohort - Stroke Questionnaire

We are contacting you following on from the South Yorkshire Cohort Health Questionnaire you completed. We would like to ask you for some information about the stroke you had and your lifestyle. This will help us to understand more about the health promotion information given out to people following a stroke.

The questionnaire will take 5-10 minutes to complete. Please complete the questions below. Once you have completed the questionnaire please send it back to the research team at Sheffield Hallam University in the pre-paid envelope provided.

As this questionnaire will be read by a data input scanner please :

- place a **cross** in boxes;
- use **black or blue ink** to complete the form;
- leave the question or section **blank** if it does not apply to you.

Section 1 - About You

Sex Male Female Date of birth / /

Section 2 - Your Stroke

We would like to know more about your stroke and how it has impacted on your life.

What date did you have your first stroke? / /

Have you had more than one stroke? Yes No

If so how many? (Enter number in box)

Thinking about your life since your stroke, tell us about any changes you have noticed in how you feel and in your daily activities.

As a result of your stroke do you have:

	Yes	No
Any problems walking about?	<input type="checkbox"/>	<input type="checkbox"/>
Any problems in washing yourself?	<input type="checkbox"/>	<input type="checkbox"/>
Any problems in dressing yourself?	<input type="checkbox"/>	<input type="checkbox"/>
Any problems in your work life?	<input type="checkbox"/>	<input type="checkbox"/>
Any problems with carrying out housework related tasks?	<input type="checkbox"/>	<input type="checkbox"/>
Any problems taking part in leisure activities?	<input type="checkbox"/>	<input type="checkbox"/>
Any pain or discomfort?	<input type="checkbox"/>	<input type="checkbox"/>
Any feelings of anxiety?	<input type="checkbox"/>	<input type="checkbox"/>
Any feelings of depression/sadness?	<input type="checkbox"/>	<input type="checkbox"/>

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Weight gain following stroke in younger age (below 70 years) in men and women: challenges and opportunities for prevention and action

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