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Living Well With a Long-term Condition: Service-users' Perspectives of a Self-management Intervention

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Abstract

The outcomes of self-management interventions are commonly assessed using quantitative measurement tools and few studies ask people with long-term conditions to explain, in their own words, what aspects of the intervention they valued. In this Grounded Theory study, a Health Trainers service in the North of England was evaluated, based on interviews with eight service-users. Open, focused and theoretical coding led to the development of a preliminary model explaining participants' experiences and perceived impact of the service. The model reflects the findings that living well with a long-term condition encompassed social connectedness, changed identities, acceptance and self-care. Health Trainers performed four related roles that were perceived to contribute to these outcomes: Conceptualizer, Connector, Coach and Champion. The evaluation contributes a grounded theoretical understanding of a personalized self-management intervention that emphasizes the benefits of a holistic approach to enable cognitive, behavioral, emotional and social adjustments.

Keywords

grounded theory; health outcomes; illness and disease, chronic; interviews; relationships, patient-provider; participation, social; quality of life; self-care; self-help

Controlled by medication and other treatments or therapies, long-term conditions (LTCs) are conditions that cannot at present be cured (Department of Health, 2012). Common conditions include musculoskeletal diseases, chronic obstructive pulmonary disease, depression, hypertension and asthma (Department of Health, 2012), with an increasing proportion of people reporting comorbidity (Office for National Statistics, 2011). The leading cause of mortality in the world, LTCs represent 63 percent of all deaths (Alwan, 2011). In England, LTCs affect around 15.4 million people (ONS, 2011) and place a disproportionate demand on health services with current estimates suggesting that care for people with LTCs accounts for around 70 percent of total health and social care expenditure (Department of Health, 2012).

With rising health service costs and frequent reports of poor rates of adherence, reduced quality-of-life and poor psychological wellbeing across different chronic conditions (Newman, Steed & Mulligan, 2004), LTC management has emerged as a key policy theme in a number of countries (Coulter & Ellins, 2009). In America, for example, the trend towards re-defining patients as co-producers rather than consumers of health care is reflected within national legislation such as the Medical Modernization Act, passed in 2003 (Coulter & Ellins, 2009). Self-management models for chronic conditions have also been widely tested in Australia and Canada and form a central feature of health policy in England (Coulter & Ellins, 2009; Department of Health, 2005, 2010, 2013). Prominent within this policy context, is the drive to ensure that people with LTCs are better equipped to manage their own conditions by improving their health literacy and involving them in planning their own care (Department of Health, 2013). This emphasis on self-management has prompted an exploration of the features and outcomes associated with interventions that shift the patient's role from one of passive recipient to active participant (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002).

In their review of self-management approaches for people with LTCs, Barlow and colleagues (2002) propose a definition of self-management that acknowledges the

psychological and social aspects of LTCs, describing it as, “an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences of life style changes inherent in living with a chronic condition” (p. 178). This holistic approach to self-management has not always been reflected in the design of self-management interventions (SMIs). SMIs have traditionally taken many different forms from group based lectures through to individualized problem-solving (Barlow, et al. 2002; Newman, Steed and Mulligan, 2004). Early approaches tended to be educational but there has been a shift from a didactic teaching model to one that is more collaborative, with the patient and professional working together to achieve the best management outcomes. Despite this shift, approaches vary considerably within and across conditions, for example SMIs for asthma tend to focus on symptom and medication management, whereas SMIs for arthritis adopt a more holistic or multi-component approach (Newman, Steed and Mulligan, 2004).

According to Newman et al. (2004), three psychological models and their constructs have informed the development of SMIs. Proponents of Social Cognition theory assert that expectations of outcome influence behavior and self-efficacy (Bandura, 1986). These ideas are reflected in SMIs designed to address teaching skills such as goal-setting to increase self-confidence. The influence of the Stress Coping Model (Lazarus, 1992) can be seen in interventions that emphasize active coping to alleviate condition-related stress, and concepts from the Transtheoretical Model (Prochaska & Velicer, 1997) are evident within SMIs that accommodate differences in participants’ readiness to self-manage.

Newman et al.’s review of 63 SMIs reveals considerable variation in the extent to which theory had been informative. They note that theory needs to be more explicitly explained within the design and evaluation of SMIs and they conclude that there is a need to establish which theoretical concepts have been used. Other reviews have highlighted persistent gaps in our understanding of the impact of SMIs and weaknesses in commonly-

used quantitative measurement tools (de Silva, 2011, 2014; Steed, Mulligan & Newman, 2009). Mathias et al. (2012), for example, note that few studies have conducted qualitative evaluations in which they ask patients to explain in their own words what aspects of the SMI they valued. Addressing this gap, and gaining an understanding of how people living with LTCs perceive, value and experience SMIs, is critical to developing responsive services that enable people to live well with their condition.

In this study, qualitative methods were used to evaluate an SMI from the perspective of people with LTCs. The focus of the investigation was a Health Trainers service managed and delivered by a Public Health service within the North of England. Introduced in the Choosing Health White Paper (Department of Health, 2004), the Health Trainer (HT) concept promotes an individualized approach to developing health-related competencies and skills. Consistent with the worldwide expansion of lay health worker programmes (WHO, 2005), HT services are delivered by lay individuals, rather than health professionals, who draw on their job related training to offer tailored, practical support to people within community settings. Typically, this support is delivered over a series of sessions, and entails goal setting, signposting to local services and supporting people through lifestyle changes (Ball and Nasr, 2011). In their review of HT evaluations, Attree et al. (2011) highlight concerns that echo the reviews of SMIs in general. They suggest that HT service evaluations are inconclusive and outcome-related data is often absent. They also highlight the lack of clarity around the theoretical basis of HT services.

The objectives of the evaluation were to explore the outcomes associated with the HT service from the perspective of people accessing the service and identify which features of the HT service were valued and why.

Design and Methods

Grounded Theory was used to address the evaluation objectives because it offered a means of understanding the outcomes associated with the HT service through an iterative process of data collection and analysis (Charmaz, 2014). Given the absence of the user perspective within the SMI literature, it was considered important to apply an approach that resisted imposing pre-existing frameworks or measures onto the evaluation.

Setting and Sample

The evaluation was conducted in a borough in the north of England. Access and consent procedures were approved by Sheffield Hallam University Ethics Committee. Participants were adults with LTCs who had met with the same HT on a number of occasions over a period of six months. Service-users were invited to take part in the evaluation by a member of the HT team, who explained the purpose of the study over the telephone, using a script that we supplied to them in advance. Initially, four service-users were recruited and invited to attend face-to-face interviews in a private room within a Local Authority building selected for its accessibility. Prior to each interview, the purpose of the study was reiterated and participants were advised of their right to withdraw. Confidentiality and anonymity procedures were also outlined. The interviews began after informed consent was obtained, and at the end of each interview participants were reminded again of their right to withdraw.

Data Collection

The audio-taped interviews were conducted over a period of two months and each interview lasted between 25 and 65 minutes. Open-ended questions were used to explore participants' experiences of the HT service, applying an interview guide (see Table 1).

Our analysis of the first four interviews highlighted a number of factors that restrict mobility, such as wintry weather conditions, poor access to public transport or severe pain. We became concerned that the expectation that we were placing on participants to travel into a town centre to be interviewed was limiting our access to the perspective of less mobile

service-users. Thus we applied Grounded Theory principles of theoretical sampling (Charmaz, 2014) and sought to recruit less mobile service-users by offering them the opportunity to take part in telephone interviews as an alternative to meeting in person. A further four service-users were recruited and subsequently interviewed over the telephone.

The principles of theoretical sampling also informed the approach to questioning participants; questions were adjusted after the first four interviews to elicit more discussion about emerging themes, such as the relevance of family and friends to positive outcomes.

Data Analysis

The recorded interviews were transcribed verbatim, anonymized and coded in three stages. The approach was informed by the version of GT articulated by Charmaz (2014), which reflects many of the basic principles of GT developed by Glaser (1978). ‘Initial coding’ (Charmaz, 2014, p.116) involved labelling the transcripts by summarising and categorising each data segment. At this point the names of the participants were removed to protect their identity. In the second stage of analysis, ‘focused coding’ (Charmaz, 2014, p.138) was applied to synthesize and explain larger segments of the text, drawing on the most significant or frequently used initial codes. This process informed the final stage of analysis, which involved the use of ‘theoretical coding’ (Charmaz, 2014, p.150) to add precision, clarity and coherence to the substantive analysis. This analytical process was applied after the first four interviews were completed, thereby ensuring that emerging themes could be identified early and explored further in the final four interviews that were conducted over the telephone.

Throughout the evaluation, ‘memos’ (Charmaz, 2014, p.162) were used to record ideas and insights that were prompted by the process of data collection and analysis. Memo-writing enabled the continuous exploration of relationships between different codes, within interviews and across participants. It made an important contribution to the process of

theoretical coding and our interpretation of the contribution of the HT service to self-management.

On completion of the study, we produced a one-page summary of the findings, which the HT service sent to each participant, along with a letter thanking them for their contribution. In the letter participants were invited to make contact if they wanted to comment on the summary or ask any questions. One participant replied, thanking us for the correspondence.

Results

The full sample comprised eight Caucasian women, age range 21 to 80 years, with a mean age of 63.5 years. LTCs affecting participants were varied and included osteoarthritis, anxiety, depression, osteoporosis and coronary heart disease. Half the participants lived alone and none were engaged in paid employment, although two were active volunteers. The number of HT sessions that participants had attended varied from two to seven, with a mean of five sessions.

The objectives of the evaluation were to explore the outcomes associated with the HT service from the perspective of people accessing the service and identify which features of the HT service were valued and why. Figure 1 presents the Four Cs model, a preliminary model based on the results of the study, that suggests how HTs impact on living well with LTCs. There are three distinct and interrelated features of this model. First, the model presents three outcomes associated with 'living well' with a LTC that were prominent in the participant interviews. In some cases participants were able to make a direct link between their HT's input and these 'living well' outcomes. This was not always possible, however, and frequently participants described a combination of factors, including the HT service, that contributed to positive change. Second, the model conveys the features of the HT service that, according to participants, enabled them to live well with a LTC. It is suggested that four HT

roles were revealed as being particularly helpful: Conceptualizer, Connector, Coach and Champion. Finally, the model highlights other influences on the 'living well' outcomes that were identified by participants. These influences constitute the wider socio-economic and local context that the HT service operates within. They have the potential to unravel or enhance outcomes associated with a HT intervention and as such they are critical to understanding the contribution of this SMI to participants' lives.

INSERT FIGURE 1 ABOUT HERE

'Living Well' Outcomes

The model reflects the findings that living well with a long-term condition encompassed social connectedness, changed identities, acceptance and self-care.

Social Connectedness: 'the importance of interacting with people to reduce the social isolation associated with living with a long-term condition'. Participants spoke about the sense of isolation that accompanies living with an LTC. Symptoms associated with their conditions, such as pain, anxiety or medication side-effects, affected confidence to leave the house. Participants also described how their motivation to spend time with other people diminished because of their low mood and a sense of being overwhelmed by their situation. Experiences of isolation were compounded by loss of a spouse or family member. Relocating to a new area to benefit from the support of family members created additional challenges: "And then moving was quite traumatic cos a lot of your memories are there. And then coming up to a completely different area where you don't know anybody. . . sometimes it felt like the walls were caving in".

Addressing this sense of isolation and building social connections was considered to be very important. Four participants discussed the many benefits that they derived from their new found or re-established social relationships. Information-sharing, companionship and practical support were referred to on a number of occasions. Regular social activity also

brought structure to participants' lives and an opportunity to re-evaluate their situation from a different perspective. One described this process in her reflections about the significance of her yoga group:

Afterwards we go to the café next door where we do yoga and quite a few will get there and gather round and we'll have a good old natter . . . passing information to each other. It's a really nice social event, you do your yoga and then you have lunch. . . And if you get out among people, you see that sometimes there are people worst than you are. And you can help them. Not physically or anything like that but just talking to them. It's just good to get out and be with people.

Changed identities: 'how participants managed disruptions to previous roles and identities by adjusting their expectations, letting go of some activities and retaining control of the important things'. Participants spoke about how living with a LTC undermined their self-identity. Their symptoms meant that they could no longer do the things they used to enjoy or perform roles that had previously been important to them: "You would love to do what you used to do but all of a sudden your rug's been pulled out from under you". The LTC represented a fracture in their life story and many described a need to come to terms with these changes. They talked, for instance, about not being as fit or active as they used to be, being unable to keep their house clean or no longer being able to make a financial contribution to the household:

Re-evaluating their identity, but at the same time maintaining a connection with their 'old self', was important. For one participant this meant retaining a level of independence despite her physical limitations, whereas for another it meant allowing her husband to take on responsibilities that she had previously protected, and "leaning on him a bit more." In one interview, a participant described how she had returned to playing the piano, but with

readjusted expectations of her abilities. In another interview, a participant spoke about how important it was for her to honor family traditions despite her limitations:

I'd only been out of hospital a fortnight and me ultimate goal, cos I'm quite a good cook, I've always been a natural cook . . . was to cook the most fantastic Christmas dinner. And I got up, cos I was pretty weak, I got up at five o'clock in the morning and I got the whole table set out and I got it all cooked. And my husband said, "Do you want any help?" And I said, "No, leave me alone" . . . We had chicken, we had pork and we had all the trimmings. We made all the table look beautiful. And I were so proud of that and then I sat down and had a cup of tea. I were absolutely jiggered. But that were my goal for the day.

This account conveyed a determination to retain family customs and maintain, or regain, a sense of control. This was a theme in a number of the interviews, although it was described in different ways, such as "not letting the label constrain you", "being in the driving seat now", or "paddling my own canoe."

Acceptance and self-care: 'managing low mood, anxiety and frustration through accepting symptoms and altered lifestyle and taking good care of self'. Referring to times in the past when they "felt down", "low" or "depressed", participants talked at length about the emotional impact of living with a LTC:

Mentally you are not yourself. You're feeling that low that you don't know what to do with yourself. . . . When I was at my worse, when I was so ill at home, I just wanted to go to bed some nights and I didn't want to wake up because that's how I felt.

Participants described feelings of anxiety, stemming from a lack of understanding of their symptoms, fear of falling, financial worries or a concern for their future. For example, "being

frightened to death of slipping” and “getting very worked up about things” were mentioned in two separate interviews. For most, living well with their condition meant accepting their symptoms and making practical adjustments that help to alleviate their anxiety or frustrations. For example, one participant said she had changed her spending patterns to accommodate her much reduced income: “when I was working I used to go round the supermarket thinking I’ll have this, I’ll have that. But now I don’t do that. I look at what I need and then I get some little luxuries.” Another spoke about how she now does the housework in stages, rather than trying to do all the cleaning and laundry in one day as she used to. She also described how she manages being housebound in bad weather:

You still have bad days, it’s no good saying you don’t. Especially winter. It’s like the ice that we had the other day - that’s not good for me. I can’t walk in that so I have to make sure I’ve plenty of things in. I have two freezers. I have a freezer in me garage and one in the house. I have to make sure there’s enough things in. That’s my way of coping.

The theme of self-care was also evident in participants’ accounts of learning to live well with their condition. They spoke, for instance, about adopting healthy eating patterns, maintaining some level of physical activity or learning to say ‘no’ more. One explanation of pacing illustrates this well:

It’s accepting that you are disabled. But it doesn’t mean that you can’t do things, you just can’t do it as fast. . . You can still enjoy some parts of your life. It’s about accepting... and that takes a lot of doing let me tell you.

The narrative of acceptance and self-care was less prominent in one account. Unlike the others,, this participant spoke about feeling very angry and frustrated that she could not leave

her house without fear of falling. Her anger was directed outwards, towards her landlord who had not agreed to cover the cost of installing an outside handrail, and to health service professionals who she felt were not attending to her debilitating symptoms:

Nothing's been done yet at all – not a thing... I've not been getting anything done with me legs, and no help with getting handrails fitted and I just think, well who do I turn to next? Do I write to Cameron [Prime Minister], or to an MP [Member of Parliament] or something, and ask them if they can help me get a rail down the path?

HT Contribution

All participants reflected positively on the support they received from their HT and links to the outcomes of social connectedness, refocused identity and acceptance were frequently made. Although the support given by their HT took many different forms, there were some consistent themes within participants' accounts of what they valued. Four HT roles were revealed as being particularly helpful: conceptualizer; connector; coach; and champion.

Health Trainer as conceptualizer: 'one who brings new perspectives, ideas and observations to help participants move from helplessness to positivity'.

Participants described how, in their early meetings with their HT, they talked about their experiences of living with their LTC. These conversations revealed difficulties or problems that they were encountering which they were then able to explore in more depth. This process was valued for a number of reasons. First, there were no boundaries to what could be discussed. Participants felt able to talk about all aspects of their lives: "Every professional has it's own niche but with S you can ask almost anything". Second, HTs used tools such as questionnaires to tease out problems or difficulties. Third, HTs brought a different perspective, which aided the process of evaluating and prioritizing people's concerns: "That was the first thing that surprised me. How he came at things from lots of different angles".

Participants spoke about how their HT was a source of ideas, for example HTs suggested resources they could try, places they could go or people they could talk to. In this way, it was suggested that HTs helped people to move from a position of feeling “stuck” or “helpless” to one in which they believed that there were possibilities and options that they could pursue:

Socially I felt cut off. I knew I couldn't just pop into town. I had to give my car up and things like that. So I was stuck but then S came into my life and showed me different things to do. It's changed my life quite a lot. . . There are all sorts of ideas I've got in my mind. It makes my life better really.

Health Trainer as connector: 'one who helps participants to access services, meet people and get support'. All the participants gave examples of how their HT had connected them with local resources. In some cases, the HT suggested suitable exercise classes or leisure groups and helped them to find a way to access these groups: “He came up with a group for people with disabilities and I've started going now. It's really, really good”. In other situations, HTs had helped participants to identify the appropriate professional to contact about their concern. For example, one described how her HT encouraged her to visit her health clinic and then accompanied her to the consultation: “She pushed me to go to my GP. She said to me, ‘You need to do this because it's upsetting you’.” The HT's role as ‘connector’ clearly extended well beyond that of information-provider; it also involved helping people to overcome the physical or psychological barriers that were preventing them from benefitting from local resources.

Health Trainer as coach: 'one who teaches, explains and encourages participants in the use of tools, resources and techniques that promote helpful behavior'. A number of participants talked about how the input of their HT enabled them to

establish more helpful patterns of behavior in their day-to-day lives. Specific tools or resources were mentioned on a number of occasions such as using a Food or Exercise Diary to encourage healthier eating routines or using audio tracks to aid relaxation and reduce anxiety. The contribution of the HT included signposting to appropriate resources, explaining or demonstrating how to use them and monitoring progress:

My diet was absolutely appalling at the time. I suppose I was most probably somewhere along the line of depressed. . . The first thing he set me on was to write out everything I ate and to try and concentrate on trying to get back the pattern of three meals a day because that had gone completely out of the window. . . I had to fill it out for a fortnight until I saw him and then we had to go over it and he made various comments. . . And then because of other things happening I managed to get my head into gear. I shifted one and three quarter stone.

She gave me a CD, which I found extremely useful. It was about how to relax. I listened to it. Well I still do listen to it. . She said to me, “Try and listen to it at a specific time in the day.” And I did, after I’d had my breakfast. And she explained things to me . . .In fact she went on a walk with me and as we walked she told me the things to look out for. Like looking at the sky and thinking about what it was like. . . I think my mind is more settled now and I can relax more. I’m a born worrier but I’m certainly better than I was. If I feel a bit worked up when I’m out and I do this breathing, it does calm me down.

Health trainer as champion: ‘one who takes an active interest, listens and encourages, giving participants the sense that they have someone on their side’. The relationship between these participants and their HT was considered to be an important source

of support and motivation. HTs listened patiently without judgment and tried to understand their experiences: “I had a lot of issues going on in my life...and she just listened. . . It felt like I’d released this big balloon of air”. They offered helpful suggestions and took an active interest in their clients’ progress, believing in their abilities and noticing and praising their achievements: “I don’t think I could play the piano very well when he first started coming and he would say, ‘Are you getting any further?’ He would take an interest in it and that makes a big difference”.

Those participants that previously felt very isolated, particularly valued this aspect of their relationship with their HT. One described how her HT encouraged her to consider volunteering in a new role: “She said, ‘You’d be really good at this.’ Me, not having the self-confidence, was like, ‘Oh, I don’t know’ . . . She had so much confidence in what I could do. It was nice.”

Other Influences

Participants identified many factors that they considered to be important for living well with their condition. Sometimes these were construed as unrelated to the HT service and other times participants described an inter-relationship between the HT service and these other influences. As depicted in the Four C’s model, three themes dominated their reflections: medication and treatments; family and friends; the quality/availability of local services.

Medication and treatments. A number of the participants described how they previously or currently relied on medication and treatments to control their symptoms. Where this was the case, the effectiveness of their medication or treatment was considered to be critical to living well with a LTC. In one interview, for example, a participant described how a new combination of drugs has meant that her pain is much reduced and she is now much more mobile than she used to be. Similarly, another talked about the transformative treatment she received from a physiotherapist. Participants could not be certain that symptom-relief

could be maintained. The fluctuating nature of their condition, or the possibility that their medication might be withdrawn because of harmful side-effects, created a sense of impermanence about their situation.

So I might be good now but if I had a drug test and it showed it was damaging my kidney or liver, I'd have to come off it [medication]. If you have to be pulled off them, then your future could be completely different.

Family and friends. The contribution of friends and family was discussed at length. Three participants had chosen to move closer to their family to benefit from their help, and it was evident that most valued the emotional and practical support they derived from their spouse, siblings, children and grandchildren. This was not the case with everyone however, as one participant talked about how her caring responsibilities for other family members constrained her ability to attend to her own needs. Participants also referred to their friends or neighbors and noted the efforts they made to help out, for example, by doing the shopping or providing transport to a group. It was clear from the data that the social contact friends provided, and the concern they showed, were much valued. One participant, for example, discussed how, as a volunteer, she now benefits from an expanded social network:

On days when I'm not too good I'll get people ringing up and saying, "How are you doing?" I've made friends who will keep in touch and say, "Do you want to come out for a meal?" So it's not too bad.

Local services. Involvement in local services made an important contribution to participants' sense of living well with their condition. Cultural groups, yoga groups, Expert Patient Programmes and physical activity sessions for people with LTCs were all referred to during the interviews. One participant talked about how her confidence in her physical

abilities grew as a result of regularly attending local gym sessions for people with long term conditions, led by a skilled instructor:

When John [the instructor] interviewed me, I got quite upset because my confidence wasn't as it should be and I knew I had a long way to go. When I started the gym, I thought, "I'll never do it." But John said, "You only do what you feel comfortable with." He's a great teacher. And I stand at the front now and we have a right laugh with him. He's great. He's brilliant.

There was also a reference to the transformative experience of attending an Expert Patients Program for people with LTCs, which one participant attended on the advice of her HT:

I remember going onto the course and thinking, "Oh my god, what has she [HT] got me into?" But I found it absolutely brilliant. And they asked me if I'd like to become a tutor and that's what I did. Now I'm a trainer on the Expert Patients Program, giving something back.

Discussion

The Outcomes Associated with the HT Service

The first objective of this evaluation was to understand the outcomes associated with the HT service from the perspective of people with LTCs. Two general observations concerning the outcomes arise from this study. First, the results highlight the difficulties associated with differentiating discreet HT service outcomes. All the participants appraised their HTs' contribution very positively. They also, however, recognized that there were other influences in their lives that had been critical to their experiences of living with their conditions, as illustrated in the Four Cs model. These largely helpful influences included familial relationships, medication and treatment and the availability of tailored local services.

Sometimes these influences were construed as being separate to the HT service and at other times a participant's HT had been instrumental in facilitating access to other beneficial resources. This observation highlights the challenge of evaluating SMIs. The process of self-management is subject to multiple influences, which are unique to each individual. Singling out outcomes that are attributable to an SMI is perhaps misguided; a more informative approach should seek to understand how an SMI interrelates with other positive influences in individuals' lives and optimizes their impact.

A second general observation concerns the way in which outcomes were framed by participants. The HT service is a self-management intervention yet on no occasion did participants use the terms 'self-management' to explain the benefits they had derived from accessing the service, nor did they construe any positive changes as outcomes or end points. It was 'life', rather than the management of their condition, that was the focus of participants' attention. What seemed to matter most was adjustment to the psychological and physical challenges associated with their condition and active engagement in a meaningful life. The multifaceted nature of adjustment and engagement is represented in the model that we have developed. This suggests that three outcomes, or rather processes, were particularly valued: Regaining emotional strength and stability, reappraisal of role and identity and social engagement.

Support for this interpretation of the data can be found elsewhere in the literature. First, the importance of participation and engagement in life is highlighted in studies that have revealed a misalignment between the priorities and values of patients with LTCs and providers. Whereas providers might focus on treatments that maximize health benefits, patients prefer treatments that maximize their daily functioning, regardless of health implications (Teh et al., 2009; Frantsve & Kerns, 2007). Second, qualitative studies have highlighted the importance of addressing the emotional impact of living with an LTC (Busch,

2005; Snelgrove & Lioffi, 2013; de Ridder, Geenen, Kuijer & van Middendorp, 2008). De Ridder and colleagues (2008), for example, note that the expression and successful management of negative emotions associated with living with an LTC, such as fear, anxiety and sadness, brings new opportunities for social support, enhanced closeness with others and promotes health-promoting behaviors such as healthy diet and physical activity. Third, the need to reappraise role and identity is highlighted in a study by Kostova and colleagues (2014), in which people living with RA spoke about the threat that their condition posed to their roles as mothers, partners or workers. Integrating the disease into their lives and establishing a new concept of 'self-identity' was an important part of the process of acceptance for patients. Finally, evidence of the positive influence of social networks and social engagement is extensive (Soulsy and Bennett, 2015; Umberson & Montez, 2010). Studies have shown that peer support, in particular, is valued by people with LTCs. A sense of solidarity and belonging is derived from sharing experiences and the exchange of information brings opportunities for new knowledge about emotional, practical and lifestyle issues (Bremander, Bergman & Arvidsson, 2009; Taylor, Gutteridge, & Willis, 2015).

Features of the Service Valued by People with LTCs

This evaluation was untypical of many SMI studies in that it asked participants to talk about the characteristics of the intervention that they valued (Mathias et al., 2012). The results suggest that HTs performed multiple roles that, according to participants, supported them in the processes of adjustment and engagement. We have described these roles as the Four C's within our model – Conceptualizer, Connector, Coach and Champion. HTs helped participants to conceptualize their experience of living with their condition and form plans to address difficulties and realize goals. They connected participants with local services or resources and they coached participants to establish healthier patterns of behavior in their

day-to-day lives. HTs championed participants by forming a therapeutic relationship with them that helped to foster self-belief and motivation.

There is some evidence for the importance of these roles in other recent qualitative SMI studies (Teh et al, 2009; Matthias et al., 2012). Matthias et al. (2012) reported that the American veterans in their study identified the Nurse Care Manager who administered their educational SMI as integral to their ability to self-manage. The features of the Care Managers' contribution that they valued most were: Support with trouble-shooting and finding solutions to the challenges they were experiencing; goal-setting and progress-monitoring; and emotional support and encouragement. Mathias et al.'s observations about the critical nature of the therapeutic relationship between the Veteran and Care Manager resonate with the findings of this evaluation:

Because so much of self-management is, by definition, the patient's responsibility, information, support and encouragement from a caring provider appear to be an indispensable component. Yet it is frequently not discussed. Our qualitative work suggests that patients develop – and value – a strong working alliance with the provider who is administering the self-management education. (p. 1024)

Consistent with Matthias et al.'s observations, Teh and colleagues (2009) reported that the patients in their study, who were receiving patient-centred treatment for chronic pain, placed a high priority on having a meaningful relationship with their provider: "They wanted their providers to sympathize with their pain and disability, to understand the psychosocial context in which they lived and experienced pain, and to know them as a whole person" (p.525). The motivating power of empathy is also highlighted in the many studies that have reported a relationship between an empathic clinician and adherence to treatment (Dobkin, Sita & Sewitch, 2006; Banja, 2006).

This evaluation therefore corroborates findings in other studies that the providers of SMIs perform multiple roles that address cognitive, behavioral and emotional aspects of life with an LTC. The proposed model also extends previous research by suggesting that an additional valued function of SMIs is that of social-connector. HTs provided a bridge to other community resources or assets that ranged from local tailored exercise classes, to peer-led educational programmes, local volunteering opportunities and social/cultural groups. In this way they became ‘social prescribers’, linking people who are regular users of primary care services to non-medical forms of support within the community (Horne, Khan and Corrigan, 2013). The potential benefits associated with social prescribing, particularly in the context of enabling people to live well with LTCs, is gaining increased attention within England (Horne, Khan and Corrigan, 2013; The Health Foundation 2013, Age UK, no date). This evaluation suggests that people with LTCs value a service that considers their social context and promotes their engagement with a wider infrastructure of support.

Psychological Models and Their Constructs

There is some support within this evaluation for the theoretical models and constructs that, according to Newman (2004), have informed SMIs. Lazarus and Folkman’s Stress and Coping Theory (1984) posits that there are several important factors involved in the coping process: The individual’s stress experience, appraisal of the available resources and his or her thoughts and behavior to manage the demand. The concept of coping as a dynamic transactional process resonates with this study’s findings that living well with an LTC requires ongoing effort to adjust to challenges and maintain active engagement in a meaningful life. Lazarus and Folkman’s suggestion that individuals have access to internal and external resources that influence their ability to cope, is also relevant. The concept of resources can be helpfully employed to interpret the different HT roles described in this evaluation. HTs, we would argue, help to harness resources in four different domains: As

conceptualizers they activate cognitive resources, as connectors they help to optimize social resources, as coaches they mobilize behavioral resources and as champions they help to preserve and utilize emotional resources. This research suggests that the Stress and Coping Theory could be usefully employed to inform the design and evaluation of SMIs for people with LTCs, particular in cases where the intervention operates outside a strictly clinical setting. As de Ridder and Schreurs (2001) highlight, the process of coping has been explicitly addressed in very few SMI studies. The results of this evaluation suggest it might be fruitful to address this gap.

The Transtheoretical Model of behavior-change proposes that individuals might be at different stages of preparedness for behavior change (Prochaska and Velicer, 1997). These stages include precontemplation, contemplation, preparation, action and maintenance. The results of this evaluation provided little support for the linearity of this model and its individual focus. The participants' interviews suggested that they oscillated between different stages of behavior activation depending upon which part of their lives they were discussing. In one interview for example, a participant described how she was making efforts to change her diet (Action) but had not yet found a way to address other family-related stressors in her life despite being aware of the need to do so (Contemplation). This finding is consistent with Snelgrove and Lioffi's study (2013), which demonstrated the irregularity of the chronic illness trajectory and the fluctuating experiences of people with LTCs. The Transtheoretical Model suggests that the barriers that inhibit people from taking action are located at the level of the individual, yet the findings from this study suggest that this is often not the case, for example participants with arthritis referred, on a number of occasions, to the difficulties associated with remaining active in cold weather. Generally, the results of this study suggest that self-management outcomes are governed by a more complex and less stable interplay of

intrapersonal, social and environmental influences than the Transtheoretical Model would suggest.

A third theoretical concept that has been applied to SMI studies is self-efficacy, which is defined as the confidence that an individual has to successfully execute a course of action to produce a desired outcome (Bandura, 1986). Numerous questionnaire-based chronic pain studies have identified a positive link between self-efficacy and adaptive functioning of patients (Jackson et al., 2014; Keefe et al., 2004), prompting calls for more investigations into the characteristics of SMIs that can enhance self-efficacy (Keefe et al., 2004). According to Bandura (1986), self-efficacy is enhanced by specific techniques from Social Cognition Theory which include modeling, mastery experiences and social reinforcement. These sources of self-efficacy reflect, in part, the features of the HT service valued by participants. The benefit of social reinforcement, for example, was emphasized in the participants' references to the direct encouragement their HT provided as champion. Similarly, the notion of mastery experiences can explain why the coach role of the HT was appreciated. There is however a disjuncture between Bandura's emphasis on modeling and the findings of this evaluation. Whereas Bandura proposed that it is upwards social comparisons that inspire action, some participants in this study described how it helped them to meet people who were in a "worse" situation to themselves. This pattern is more reminiscent of the downward evaluations that Taylor and Lobel (1989) reported in their interpretation of how cancer patients adjust positively to their disease.

In summary, we have suggested that there is, within this evaluation, mixed support for the three psychological models that have been most commonly associated with SMIs. The theory that appears to offer the most relevant overall framework is the Stress Coping Model. Features of the HT service valued by participants also resonate with Bandura's ideas about the drivers of self-efficacy. The discussion has also revealed the possible value of using concepts

within Taylor's Theory of Cognitive Adaptation to interpret how SMIs promote positive adjustment. Our suggestion that a number of theories offer useful constructs and relationships for interpreting the contribution of a SMI poses a challenge for those involved in their design. Translating these ideas into practice, operationalizing the concepts and integrating different models is potentially very difficult. One response to this is to develop a grounded theoretical understanding of the intervention and then map the emerging constructs and relationships against a meta behavior-change framework, such as the COM-B model (Michie, Atkins & West, 2014). COM-B recognizes that behavior is part of an interacting system that involves psychological or physical ability (Capability), the physical and social environment (Opportunity) and reflective and automatic mechanism (Motivation).

Limitations, Application and Future Research

The sample was composed of participants who, having accessed the HT service for at least six months, had shown a prolonged commitment to better manage their condition. This immediately introduced a bias into the study and, had we sought the views of those that had accessed the service only once or twice, we might have elicited a different pattern of data. Nevertheless, we believe that the approach to sampling was justified on the basis that the aim was to explore positive outcomes and features of the service. Another limitation of the sample was that it only consisted of white women who were mostly over 60 years of age. In future studies, it would be useful to expand the sample in order to explore whether the categories presented in the Four C's model are applicable to different sub-populations and a wider range of LTCs. These adjustments would help to elucidate the theoretical constructs and relationships and highlight whether the proposed model achieved 'theoretical sufficiency' (Dey, 1999, p.257).

It is possible that the model that we propose is based on unreliable or partial data. Participants might have withheld information out of fear that it would be relayed to the HT

service, despite being informed that their responses were confidential. It is, however, unlikely that this compromised the analysis given that the focus was on what participants valued about the service. To develop the proposed model we could return to the participants and explore some themes in more depth. An interesting extension of the research would be to invite the HTs to discuss the findings in a focus group. This would reveal the extent to which they feel the key themes reflect their experiences. Should further research endorse this model, the findings could be disseminated to those involved in HT recruitment, training and development.

Michie, Atkins and West (2014) recently noted that frequently intervention designs are arrived at “before having conducted a thorough assessment of the appropriate behavioral target(s), what it would take to achieve change in these and how best to implement this” (p.14). This study offers a preliminary assessment, which has the potential to inform the design and evaluation of other SMIs. As a qualitative evaluation, it proposes a nuanced person-centred interpretation of self-management, which extend well beyond symptom-management or a healthy lifestyle. Living well with an LTC encompasses psychological adjustment, social engagement and adjusted self-identity and life goals. These themes, which are prevalent in other qualitative investigations of self-management, offer a framework for developing and reviewing self-management intervention strategies. Similarly, the roles of the HT identified within this evaluation, suggest a framework for mapping and reviewing the primary functions of SMIs, particularly those that are located within a non-clinical setting.

Very few SMIs make explicit reference to theoretical models or concepts from the field of health psychology to inform their design or evaluation (Newman, 2003). This study suggests that a number of theories offer relevant constructs and ideas, however it is also noted that there are challenges associated with their integration and application. As a meta-model of behavior change, COM-B (Michie, Atkins & West, 2014) seeks to encapsulate ideas from a

number of theories. Further research could, therefore, investigate whether COM-B provides a framework for interpreting the themes and relationships that emerge from the findings of this evaluation.

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References

- Age UK. (No date). Social Prescribing – a model for partnership working between primary care and the voluntary sector. Retrieved from <http://www.ageconcernyorkshireandhumber.org.uk/uploads/files/Social%20Prescribing%20Report%20new.pdf>
- Alwan, A. (2011). *Global status report on noncommunicable diseases 2010*. World Health Organization
- Attree, P., Clayton, S., Karunanithi, S., Nayak, S., Popay, J., & Read, D. (2011). NHS health trainers: a review of emerging evaluation evidence. *Critical Public Health*, 22, 25-38.
- Ball, L., & Nasr, N. (2011). A qualitative exploration of a health trainer programme in two UK primary care trusts. *Perspectives in Public Health*, 131(1), 24-31.
- Bandura, A. (1986). *Social foundations of thought and action: a social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall.
- Banja, J. D. (2006). Empathy in the physician's pain practice: Benefits, barriers, and recommendations. *Pain Medicine*, 7(3), 265-275.
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counselling*, 48, 177-187.
- Bremander, A., Bergman, S., & Arvidsson, B. (2009). Perception of multimodal cognitive treatment for people with chronic widespread pain - Changing one's life plan. *Disability and Rehabilitation: An International, Multidisciplinary Journal*, 31(24), 1996-2004.
- Busch, H. (2005). Appraisal and coping processes among chronic low back pain patients. *Scandinavian Journal of Caring Sciences*, 19(4), 396-402.
- Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). London, UK: SAGE.

- Coulter, A., & Ellins, J. (2009). Changing attitudes to the role of patients in health care. In S. Newman, L. Steed & K. Mullian (Eds.), *Chronic physical illness: self-management and behavioural interventions* (pp.28-44). Maidenhead, UK: Open University Press.
- de Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet*, 372(9634), 246-255.
- de Ridder, D., & Schreurs, K. (2001). Developing interventions for chronically ill patients: Is coping a helpful concept? *Clinical Psychology Review*, 21(2), 205-240.
- de Silva, D. (2011). *Helping people help themselves: a review of the evidence considering whether it is worthwhile to support self-management*. London, UK: The Health Foundation.
- de Silva, D. (2014). *Helping Measure Person Centred Care*. London, UK: The Health Foundation.
- Department of Health. (2004). *Choosing health. Making healthy choices easier*. Retrieved from http://webarchive.nationalarchives.gov.uk/+/dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4094550
- Department of Health. (2005). *National service framework for long term conditions*. Retrieved from <https://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions>
- Department of Health. (2010). *Healthy lives, healthy people: our strategy for public health in England*. Retrieved from <https://www.official-documents.gov.uk/>
- Department of Health. (2012). *Long term conditions compendium of information: Third Edition*. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf

- Department of Health. (2013). *The NHS outcomes framework 2014/15*. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256456/NHS_outcomes.pdf
- Dey, I. (1999). *Grounding grounded theory*. San Diego, CA: Academic Press.
- Dobkin, P.L., Sita, A., Sewitch, M.J. (2006). Predictors of adherence to treatment in women with fibromyalgia. *Clinical Journal of Pain*, 22(3), 286-294.
- Frantsve, L. M., & Kerns, R. D. (2007). Patient provider interactions in the management of chronic pain: Current findings within the context of shared medical decision making. *Pain Medicine*, 8, 25-35.
- Glaser, B. G. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Horne, M., Khan, H. & Corrigan, P. (2013). *People powered health: health for people, by people, with people*. London, UK: Nesta.
- Jackson, T., Wang, Y., Wang, Y., & Fan, H. (2014). Self-efficacy and chronic pain outcomes: A meta-analytic review. *The Journal of Pain*, 15(8), 800-814.
- Keefe, F. J., Rumble, M. E., Scipio, C. D., Giordano, L. A., & Perri, L. M. (2004). Psychological aspects of persistent pain: Current state of the science. *The Journal of Pain*, 5(4), 195-211.
- Kostova, Z., Caiata-Zufferey, M., & Schulz, P. J. (2014). The process of acceptance among rheumatoid arthritis patients in Switzerland: A qualitative study. *Pain Research & Management*, 19(2), 61-68.
- Lazarus, R.S. (1992). Coping with the stress of illness. *WHO Regional Publications European Series*, 44, 11-31.
- Matthias, M. S., Miech, E. J., Myers, L. J., Sargent, C., & Bair, M. J. (2012). An expanded view of self-management: Patients' perceptions of education and support in an intervention for chronic musculoskeletal pain. *Pain Medicine*, 13(8), 1018-1028.

- Michie, S., Atkins, L., & West, R. (2014). *The Behaviour Change Wheel: A Guide to Designing Interventions*. London, UK: Silverback Publishing.
- Newman, S., Steed, L., & Mulligan, K. (2004). Self-management interventions for chronic illness. *The Lancet*, *364*, 1523-1537.
- Office for National Statistics. (2011). *General lifestyle Survey overview. A report on the 2009 General Lifestyle Survey*. Retrieved from <http://www.ons.gov.uk/ons/rel/ghs/general-lifestyle-survey/2009-report/index.html?format=hi-vis>
- Prochaska, J.O., & Velicer, W. F. (1997). The transtheoretical model of health behaviour change. *American Journal of Health Promotion*, *12*, 38-48.
- Snelgrove, S., & Lioffi, C. (2013). Living with chronic low back pain: A metasynthesis of qualitative research. *Chronic Illness*, *9*(4), 283-301.
- Soulsby, L., & Bennett, K. (2015). How relationships help us to age well. *The Psychologist*, *28*(2), 110-113.
- Steed, L., Mulligan, K., & Newman, S. (2009). Development and evaluation of self-management interventions. In S. Newman, L. Steed & K. Mulligan (Eds.), *Chronic physical illness: self-management and behavioural interventions* (pp.135-147). Maidenhead, UK: Open University Press.
- Taylor, F., Gutteridge, R., & Willis, C. (2015). Peer support for CKD patients and carers: Overcoming barriers and facilitating access. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy*. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/hex.12348/epdf>
- Taylor, S.E., & Lobel, M. (1989). Social comparison activity under threat: downward evaluation and upward contacts. *Psychological Review*, *96*, 569-575.

Teh, C. F., Karp, J. F., Kleinman, A., Reynolds, C. F., III, Weiner, D. K., & Cleary, P. D.

(2009). Older people's experiences of patient-centered treatment for chronic pain: A qualitative study. *Pain Medicine*, 10(3), 521-530.

The Health Foundation. (2013). *Implementing shared decision making – learning report*.

London, UK: The Health Foundation.

Umberson, D., & Montez, J.K. (2010). Social relationships and health. *Journal of Health and Social Behaviour*, 51, 554-566.

World Health Organization. (2005). *Report of the WHO Task Force on Health Systems Research*. Geneva: World Health Organization, 2005. Retrieved from

http://www.who.int/rpc/summit/en/Task_Force_on_Health_Systems_Research.pdf

Bios

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Table 1. Interview Guide Questions

Question	Focus
Can you tell me what circumstances led you to make contact with the Health Trainers service? What were you hoping to gain from the service?	Initial motivations
I'd like to hear about whether your experience of your condition has changed since you started seeing a Health Trainer. Can you tell me about anything you are doing differently now? How has this changed the way you think or feel about your condition?	Impact on behaviour and thoughts and feelings
Can you tell me about how these changes are impacting on your life generally?	Impact on life generally
In what ways has the Health Trainers service contributed to these changes? Do you think the Health Trainers service could have done more to help you manage your condition? If so, what?	Features of HT service: strengths and limitations
Is this support different to support that you have had from other health professionals in the past? How is it different? *	Comparison with other sources of support
What role do you think you have played in bringing about these changes? Do you think that there is more that you could have done yourself? What gets in the way of you helping yourself?*	Personal contribution: enablers and barriers
Other than your health trainer, has anyone else helped you to make these changes (such as friends, family or other health professionals)? How have they helped you? Is there anything more that they could have done to help you?*	Contribution from others: enablers and barriers
How confident are you that the changes we've been discussing will continue? Why do you say this? How important is it to you that you stay in touch with the Health Trainers service? Why do you say this?	Confidence to self-manage beyond HT service

* These questions were introduced in response to theoretical sampling

