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Title: 'The care that you give to yourself': a qualitative study exploring patients' perceptions of self-care

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Abstract

Introduction: Self-care incorporates a range of activities undertaken by patients including health protection and maintenance, treatment of minor ailments and the self-management of chronic conditions. The present study aimed to explore patients' perceptions of self-care, including factors which might promote, or hinder, patients' engagement with self-care strategies.

Methods: A qualitative approach was adopted. A sample of 20 patients with chronic conditions participated in the study. Seventeen interviews and one focus group were audio recorded and transcribed verbatim. Transcripts were analysed thematically using Framework methodology.

Results: Participants identified five dimensions to the concept of self-care (1) taking responsibility for one's health and lifestyle choices, (2) reflecting on own needs, (3) being an expert of oneself, (4) doing things for oneself (self-agency), and (5) adopting lifestyle activities to support health and wellbeing. Participants identified a number of factors which had facilitated the initiation of their self-care activities. These included having accurate advice/information to inform decision making; having encouragement from treating healthcare professionals; having the right attitude and outlook; and having the motivation to initiate self-care. Factors which could hinder the initiation of self-care included symptoms of their chronic condition, and socioeconomic, cultural, and environmental factors.

Conclusions: Patients appear to have a complex and multifaceted understanding of self-care. The identified factors which facilitated or hindered participants in adopting self-care activities have important implications for the provision of self-care advice by treating health care workers, and the delivery of self-care services more widely.

Background

The concept of self-care is broad, and typically incorporates the range of activities undertaken by patients including health protection and maintenance, treatment of minor ailments and the self-management of chronic conditions. The World Health Organization (WHO) defines self-care as “the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider”.[1] Inherent in the concept of self-care is the recognition that it is individuals themselves who act (or not) to preserve health and respond to symptoms [1]. The term self-care is often used interchangeably with that of self-management, however self-management is usually used in relation to how patients manage long term chronic conditions only, with self-care also incorporating the preventative and health protective activities of healthy individuals as well [2].

Self-care, and in particular self-management, interventions have increasingly become an essential component of national health systems around the world. Many prevalent chronic illnesses, such as heart disease, diabetes, asthma and arthritis, require patients to monitor physical indicators, manage medication regimes and components of their lifestyle such as diet and exercise. There are now many published studies which have explored how patients self-manage their long term chronic conditions, or which evaluate interventions designed to aid patients to self-manage these chronic conditions [for example see 3-6] Despite this wealth of research evaluating the effectiveness of self-management interventions for long term chronic conditions, few published studies have explored patients' perceptions and understanding of 'self-care', ie not merely the management of a chronic condition, but also their perceptions of preventative and health protective activities they also engage in, or use to manage minor ailments as they develop.

The Royal London Hospital for Integrated Medicine (RLHIM) is located within University College London Hospitals (UCLH) National Health Service (NHS) Trust and is the largest public sector provider of integrated medicine in Europe. The hospital has recently launched a dedicated self-care service, to assist patients to manage their health and long term chronic conditions. Given the limited amount of research exploring patients' perceptions of self-care, a qualitative study was conducted to explore patients' perceptions and understanding of self-care, and to identify factors which might promote or hinder utilisation of self-care activities. The findings of the study will be used to inform the RLHIM self-care service, including the interventions provided and modes of delivery.

Methods

A qualitative approach was adopted to explore patients' perceptions of self-care, and identify factors which may promote, or hinder, patients' engagement with self-care strategies. A random sample of 200 NHS outpatients who had attended either RLHIM or the adjacent National Hospital for Neurology and Neurosurgery (NHNN) were invited to participate in the study. Patients were selected from RLHIM/NHNN clinics known to include conditions amenable to improvements from self-care approaches (fibromyalgia; musculoskeletal conditions; movement disorders; chronic fatigue; and, multiple sclerosis). As large numbers of patients routinely use these services the decision was made to invite a random sample of 200 patients to take part in the study (40 patients from each of the five services). This was to ensure that the study sample had patients represented with each condition, and that all those invited who wanted to participate were able to. Invitations were only sent to patients who had attended a RLHIM/NHNN clinic within one month prior to the randomisation process, who resided in Greater London, and were older than 18 years old. In addition it was an inclusion criteria that patients had a sufficient ability to understand English (as judged by the researchers), and be willing to participate in the study and take part in an interview/focus group; however, no patients were excluded on this basis.

Randomisation was performed by a member of RLHIM staff not involved in the research study using a random number generator. An invitation letter and patient information sheet for the study was posted to selected patients, explaining what participation entailed and their rights as a participant. Interested patients returned a contact sheet to a member of the research team who subsequently telephoned them, discussed the qualitative study, obtained verbal consent, and arranged either a one-to-one interview or focus group depending on patient preference. All patients willing to participate were interviewed. Seventeen interviews and one focus group were arranged at RLHIM at a time convenient for patients. Participants were able to claim their travel expenses to attend the interview/focus group. Interviews/focus group were conducted between March 2018 and July 2018. All interviews/focus group were conducted by the same member of the research team (JH). Patients provided written consent immediately prior to the interview/focus group.

The interviews/focus groups were directed by a topic guide. The main areas which were explored within the interviews/focus group were patients' understanding of the term 'self-care', their experiences of using self-care strategies, factors which they felt facilitated or hindered their engagement with self-care, and what self-care activities or services they would like to see provided within the NHS. In each case participants were initially asked broad open-ended questions, with follow up probing questions used where appropriate. The topic guide was updated throughout the study to incorporate emerging themes. Interviews/focus group were audio recorded and transcribed verbatim. The interviews and focus group lasted for between 30 and 90 minutes. Transcripts were analysed thematically using Framework methodology, a manual, matrix method, which facilitates thematic and cross-case interpretation.[7,8] Analysis proceeded in five stages:

- Familiarisation. Transcripts read and re-read by members of the research team to familiarise and immerse in the data.
- Identification of the thematic framework. Key issues, concepts and themes arising from the data were identified by the research team, and grouped thematically to construct a conceptual framework.
- Indexing. Three of the research team independently applied the thematic framework to the same transcript to explore any differences in application. The thematic framework was then applied systematically to all the data (NB).
- Charting. Thematic matrices were constructed for all identified categories/subcategories to further summarise and synthesise the indexed data (NB).
- Detection, categorization and classification. The original research questions were reconsidered, and the charts examined in order to define concepts, map the range and nature of phenomena, find any associations and provide explanations (NB).

Ethical approval for the qualitative study was obtained from the Office for Research Ethics Committees Northern Ireland [REC reference number: 14/NI/0007].

Sample

A sample of 20 RLHIM/NHNN patients participated in the qualitative study. Thirteen patients had primarily received treatment at RLHIM, and 7 from the NHNN (some patients had received treatment from both hospitals). Six participants had primarily been referred for fibromyalgia, 5 for musculoskeletal conditions, 4 for movement disorders, 3 for chronic fatigue and 3 for multiple sclerosis. The age range of the participants was 36-83 years (mean 58.4 years), and 14 were female and 6 male. Seventeen participants took part in one-to-one interviews, and 3 participated in a focus group.

Results

Analysis of the qualitative data revealed major categories and sub-categories relating to patients' perceptions and experiences of self-care. Major categories were linked to the aims of the study and included '*perceptions of self-care*', '*practice of self-care*', and '*future self-care services*'.

Perceptions of self-care

Participants identified five dimensions to their concept of self-care. These included, (1) taking responsibility for one's health and lifestyle choices, (2) reflecting on own needs, (3) being an expert of oneself, (4) doing things for oneself (self agency), and (5) adopting lifestyle activities to support health and wellbeing (typically exercise, diet, meditation, and education). Collectively, participants indicated self-care was utilised to support the mental, physical, social and spiritual aspects of their health.

'Self-care is like the care that you give to yourself I think.' [SC07]

'Things you can do for yourself to optimize your health and condition, whatever they may be whether it's exercise, meditation or whatever.' [SC14]

'I define self-care as, number one is responsibility, I take responsibility for my actions. Whether it's psychological, whether it's emotional, whether it's physical, or whether it's spiritual.' [SC17]

Participants' understanding of self-care was found to be influenced by a number of factors. These factors included participants' beliefs about health generally; the amount of time spent with, and nature of their interactions with, treating healthcare professionals; whether they had made a conscious decision to educate themselves regarding self-care; their access to relevant information; and the exchange of information between themselves and others with the same condition (shared knowledge, experience, understanding, and encouragement).

Participants' perceptions of the nature of their interactions with healthcare professionals regarding self-care advice varied considerably. Most participants indicated that they felt that no treating healthcare professional had ever provided any advice or guidance relating to self-care initiatives which they could employ to help manage their health and chronic condition. Those who had received self-care advice tended to indicate that this consisted of suggesting lifestyle changes, often in a collaborative approach between patient and healthcare professional. However, it should be noted that in some cases participants highlighted that they felt they had received conflicting advice from different healthcare professionals. It is also worth noting that not all participants felt the nature of self-care engagement was collaborative, with some participants indicating they felt they were dictated to regarding self-care activities ('you must do'), or felt threatened into engaging with suggested self-care activities ('attend classes or else').

'I've not had a session where someone has sat down and gone right, let's talk about all the things you can do specifically. They tend to have been, urologist or the physio or the MS nurse of the occupational health team, they've all got different areas and they discuss a few things within that area that I can do.' [SC05]

'I find as a patient a lot of the things I have to find out for myself. There wasn't anything to help me along the way.... I just found that the best they could do was really just put a prescription in your hand, and everything else I had to basically research and find myself and ask for.' [SC08]

'But self-care to me, is when the patient has equal, is an equal participant in the care. So there is the clinician and the patient and the patient obviously has to choose the intervention, but there is that dialogue between the clinician and the patient, at the moment it's too weighted in favour of the clinician in terms of empowerment.' [SC09]

'Self-care, no one has mentioned that word at all in the neurology side to me at all.' [SC10]

Outside of clinical encounters, participants indicated they accessed self-care information through a variety of channels with the internet providing access to many of these. These included patient forums, journals, documentaries, and attending relevant classes. Participants learnt through exploration what worked for them and what didn't, by modifying aspects such as diet, supplementation, and home aids, as well as through time spent with peers with whom they had shared experiences and understanding.

The participants identified that conflicting approaches to healthcare can create tensions between healthcare professionals and patients and effect treatment outcomes. Some were cautious about adopting the assumption that all advice given from within the NHS was up to date and rigorous. Many desired an evidence based approach to self-care advice, as opposed to having to rely on the personal experiences of others within formats such as online forums.

'The long-term condition part, you want a bit more evidence and things there to do this wellbeing thing, and it's not really there because you're getting very conflicting information.' [SC10]

Practice of Self-care

The types of self-care practiced by participants in this study varied from good nutrition through to exercise, relaxation techniques and using complementary and alternative methods of healthcare. Particularly for chronic fatigue, multiple sclerosis and fibromyalgia participants, planning, pacing and modifying activities accordingly was often seen as an important self-care practice. Likewise a number of participants also highlighted the importance of ensuring they had sufficient rest and sleep as being important in their self-care. Participants had initiated a wide variety of self-care activities, with varying degrees of perceived benefit to their health condition or overall wellbeing. Importantly participants engaged in these self-care activities in a trial and error fashion, maintaining those that worked for them and abandoning those which didn't.

'You learn what works for you because what works for someone else might not help you at all.' [SC05]

'Alexander technique I have to say as I said is fantastic, and yes I would say Alexander and homeopathy and the acupuncture actually did help.' [SC11]

Participants identified a number of factors which had facilitated the initiation of their self-care activities. These included having accurate advice/information to inform decision making; having encouragement from treating healthcare professionals (perceived as being part of having a good therapeutic relationship); having 'the right attitude' and being open to the idea of managing their own health and chronic condition; having the motivation to initiate self-care (which was typically underpinned by a desire to be well and wanting to pursue interests and things they loved); and finally having the confidence to ask for more information when needed was also identified by some participants as a factor in facilitating their initiation of self-care activities.

With regards to factors which participants felt had or could hinder the initiation of self-care, participants highlighted symptoms of their chronic condition, particularly pain, depression and fatigue, as being able to impede and de-motivate them in undertaking self-care activities. Other factors were linked to personal circumstances including socio-economic (lack of finances to access, or travel for, self-care activities), and cultural and environmental conditions of health such as living and working conditions, and unemployment.

'I used to go swimming regularly at lunchtimes, and I got slower and slower due to my symptoms, and it got to the point where I was just completely beaten after swimming for 20 minutes, so I stopped doing it.' [SC05]

'It's a shame that someone can not do something because they can not afford it, it's like someone can not eat because they don't have money it is shameful it is really sad. Its really sad that someone can not have access to a service.' [SC07]

'I've already payed an extortionate amount of money to go to Chinese acupuncture, to pay for osteopathy, chiropractors, some worked, some didn't.' [SC08]

Future self-care services

Each participant had their unique ideas about what self-care services they would like to see provided within the NHS. However, all typically perceived that any self-care provision should be holistic in nature and individualised to patient's specific requirements. Most participants were keen on group formats with self-care activities, where possible, to enable patients to share their experiences and provide peer support. Many participants highlighted that they felt there should be increased provision of self-care services within the NHS, with greater provision and access to information and therapeutic support (typically counselling/psychotherapy). Participants highlighted a range of self-care activities which they would like to see provided, ranging from lifestyle activities such as nutrition and cooking, to psychological interventions such as mindfulness and CBT, mind-body techniques such as Tai Chi and yoga, as well as self-care complementary approaches such as the Alexander Technique. All participants had personally paid for some self-care activities, and most indicated they would be willing to pay for self-care services within the NHS if it was affordable to them and they felt they would be beneficial to their health and wellbeing.

'The group session, by far, the biggest takeaway for me is, is not the things they're talking about as part of the session, it's the interaction with other MS sufferers, finding out what they do, you know, simple stuff like, oh you know, always get really hot at night, a silk pillow case really, really helps and I was "wow" I would, you know, never come across that talking to a professional.' [SC05]

With regards to how participants would like to see self-care provided, again views differed, with most highlighting that different modes of delivery would be good for different self-care approaches. These included providing YouTube/apps/social media resources; one-to-one sessions with therapists to enable patients' individual stories to be heard; where appropriate group work delivered by clinicians; as well as traditional leaflets/books. The importance of healthcare professionals having longer appointment times to capitalise on information exchange/building therapeutic relationships was also highlighted by some participants.

'I think seeing a specialist and probably having kind of a group session where you, you know, they are similar kind of cases, it does help a lot.... I think that that would be helpful, you know, I mean these fact sheets and that kind of courses do also help I feel.' [SC04]

'Self-care could be a sort of learning, a mutual learning area, the hospital learning from patients, patients learning from people that were being brought in to explain the condition, talk about new research, new ideas, a sort of melting pot really of, to sort of empower people to take charge of their condition really.' [SC09]

'Have information about where people could look for information.... maybe a place to go for resources and listening is the easiest way to take it in I would say as well rather than reading. You could recommend books on nutrition, so what I'm saying is, leaflets giving people places they can go to, places they can go to, books they can refer to, to help them.....you know, books or websites that people could visit.' [SC13]

Discussion

Previous studies have explored patients' perception of self-managing chronic long term conditions, or have evaluated self-management interventions for patients with chronic long term conditions [3-6]. In contrast the present study is one of the first to explore patients' perceptions of self-care, including not just how they manage a chronic long term condition, but also their perceptions of preventative and health protective activities they also engage in, or use to manage minor ailments as they develop. The participants in the present study identified various dimensions to their concept of self-care, suggesting a complex and multifaceted understanding of self-care. Participants' understanding of self-care included reflecting on their needs, taking responsibility for their health and lifestyle, being an expert of oneself, self-agency, and adopting lifestyle activities to support health and wellbeing. Participants conceptualisation of self-care appears to be fairly congruent with established definitions of self-care [1,2]. Where it differs is in the notion within some definitions, such as that of the WHO [1], that self-care also includes those outside of the individual themselves, ie their family and community, with none of the participants perceiving their own self-care to extend to their family and wider community. Participants in the present study were found to perceive self-care as not merely the management of the symptoms of their chronic conditions, but also activities they undertook to support the mental, physical, social and spiritual aspects of their overall health. As part of this wider process of self-care, participants were found to have used and/or desire, a variety of initiatives, ranging from lifestyle activities such as nutrition, psychological interventions such as mindfulness, mind-body techniques such as Tai Chi and yoga, as well as self-care complementary approaches such as the Alexander Technique.

A number of previous studies have explored factors which can facilitate or hinder patients' engagement with self-management initiatives for long term chronic conditions [9-12]. The findings from this study reinforce the importance of certain factors to the successful adoption of self-management practices, whilst also highlighting their importance to self-care practices too. Previous systematic reviews and syntheses of qualitative studies consistently suggest that the provision of information, having encouragement from treating healthcare professionals, self-motivation, and self-confidence can all facilitate the successful adoption of self-management initiatives. These reviews and syntheses also indicate that, for many patients with chronic conditions, symptoms of their condition, particularly pain, depression and fatigue, frequently hinder patients in their attempts to self-manage. Previous studies have also consistently found that socioeconomic factors, including finances and living and working conditions, can also hinder patients from being successful in their self-management [9-12].

Importantly the interpretive synthesis which was conducted by Harvey and colleagues [10], suggests that factors depicted as facilitators or barriers can have pluralistic (sometimes opposing) meanings, and are influenced by the context within which stakeholders place self-care/self-management solutions. For example, as in the present study social support has been strongly expressed in many qualitative studies as a facilitator to the adoption of self-management interventions. However, Harvey et al found it was also reported that some patients felt 'pressured' from overly supportive family or friends, or felt they were being constantly reminded of sickness when with their peer group, and therefore experienced these types of support as a barrier [9].

Patients receiving conflicting advice was noted as a potential barrier to patients adopting self-management initiatives in the systematic review of qualitative studies performed by Liddy et al [10]. It is worth noting that the present study not only found that patients had experience of receiving contradictory advice, but also that this was perceived as negatively impacting on their self-care and treatment outcomes. For some this led to them being cautious and even critical of whether the advice they received within the NHS was current and rigorous, potentially leading to patients not adopting positive self-care initiatives. It would appear imperative to the successful delivery of self-care advice

and services that information provided to patients be consistent and evidence based. This will facilitate the adoption of positive self-care initiatives by patients with chronic illnesses, improving personal health outcomes and NHS costs.

Limitations

Due to the nature of the symptoms associated with the conditions of participants in this study, some may have chosen not to take part based on how impactful their symptoms were at the time of recruitment, or may have been unable to make the journey, and they may have different views than those who took part. The fact that participants self-selected to participate is also associated with potential bias, and as with qualitative research generally, it is not possible to generalise the findings to all patients. It is also worth noting that the study deliberately recruited patients with conditions amenable to improvements from self-care approaches, and who therefore may have greater knowledge of self-care than other patients.

Conclusions

The present study is one of the first to explore patients' perceptions and understanding of self-care. Patients appear to have a complex and multifaceted understanding of self-care, which is largely congruent with established definitions. Self-management interventions for chronic health conditions have often demonstrated both effectiveness and cost-effectiveness. However, implementing these interventions into clinical practice has frequently encountered difficulties in encouraging patients to adopt positive self-care approaches. The identified factors which facilitated or hindered participants in adopting self-care activities have important implications for the provision of self-care advice by treating health care workers, and the development and delivery of self-care services more widely. The findings also highlight the importance of health professionals forming partnerships with patients to facilitate self-care in a way that is tailored to the patient's own understanding of self-care. An evidence based approach to self-care, which can be disseminated to patients in a collaborative approach, is desired by patients and should be prioritised within national health systems.

Authors contribution

All authors had full access to the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Conceptualization, JH, RS and PF; Methodology, JH, RS and PF; Investigation, JH; Formal Analysis, NB, JH, RS and AM; Resources, JH; Writing - Original Draft, JH; Writing - Review & Editing, All.

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Declaration of competing interests

JH is the editor of the Special issue on Self-care and is an editorial board member of the European Journal of Integrative Medicine.

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Data availability

The authors can be contacted regarding the availability of the data from the study.

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