

BMJ Open Factors influencing the integration of self-management in daily life routines in chronic conditions: a scoping review of qualitative evidence

Enxhi Qama ^{1,2}, Sara Rubinelli,^{1,2} Nicola Diviani^{1,2}

To cite: Qama E, Rubinelli S, Diviani N. Factors influencing the integration of self-management in daily life routines in chronic conditions: a scoping review of qualitative evidence. *BMJ Open* 2022;**12**:e066647. doi:10.1136/bmjopen-2022-066647

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-066647>).

Received 15 July 2022

Accepted 02 December 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Person-centered Healthcare & Health Communication Group, Swiss Paraplegic Research, Nottwil, Switzerland

²University of Lucerne, Lucerne, Switzerland

Correspondence to

Dr Enxhi Qama;
enxhi.qama@paraplegie.ch

ABSTRACT

Objective Self-management of chronic diseases is regarded as dynamic experience which is always evolving and that requires constant adjustment. As unexpected and new shifts in diseases occur, patients tend to abandon acquired behaviours calling into question their sustainability over time. Developing a daily self-management routine as a response to lifestyle changes is considered to facilitate self-management performance. However, fitting self-management recommendations in one's daily life activities is a constant challenge. In this review, we describe the performance of self-management routines within daily settings in people living with chronic conditions with the aim of identifying factors that challenge its integration in daily life.

Design Scoping review.

Data sources We searched PubMed, Web of Science, CINAHL and PsycINFO on February 2022.

Eligibility criteria We included qualitative studies on self-management experience, in English, with adult participants, original and peer-reviewed, and depicting the performance of self-management activities in one's own environment.

Data extraction and synthesis Two reviewers independently screened titles and abstracts. After agreement, one reviewer screened the full text of relevant articles and extracted the data. The data were synthesised and analysed thematically. PRISMA Extension for Scoping Reviews checklist was used for reporting the steps.

Results Twenty-two studies were included. The thematic analysis brought up two overarching themes. The first one is the Environment support with three subthemes: family and cultural norms; health professionals and guiding communication; and society and disease perceptions. The second theme is comprehension gap with two subthemes: reading the body and applying information.

Conclusions The integration of self-management requirements in a daily routine is affected by the patients' inability to apply disease knowledge in different context and by the challenge of understanding body symptoms and predicting body reactions in advance.

INTRODUCTION

In healthcare self-management has been defined as 'the ability of the individual in conjunction with family, community and

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The strength of our study was the use of standards for the conduct and reporting of reviews, employed a rigorous thematic analysis process, which involved independent analysis by two researchers and several critical discussion meetings with all reviewers involved.
- ⇒ The methodology followed allowed for assessing an extensive body of literature, across different study aims, conditions and populations, which made it possible to identify gaps in the literature: longitudinal qualitative study design; education and learning needs throughout different phases and turning points in self-management integration.
- ⇒ Because of the nature of our review, a quality appraisal of the included studies was not undertaken, therefore, the strength of their evidence was not evaluated.
- ⇒ Even though we discuss our results by reflecting on the existing evidence in the field, we acknowledge that another limitation of our review is the potential exclusion of relevant studies.

healthcare professionals, to manage symptoms, treatments, lifestyle changes and psychosocial, cultural and spiritual consequences of health conditions'.¹ Patients combine medical management with other attributes that include role and emotional management.² Chronic conditions on the other side are defined as conditions that need frequent monitoring because of multiple and different symptoms and changes in physiological parameters, and that require commitment of time and effort to manage.^{3,4} Indeed, self-management of chronic diseases is regarded as dynamic and always evolving; as a result, it is not always a simple experience.⁵⁻⁷ As unexpected and new shifts in diseases occur, patients tend to abandon acquired behaviours calling into question their sustainability over time.^{8,9} For instance, experiencing a new symptom or encountering information that contradicts previous knowledge puts patients

in unknown territory to which the standard recommendations of self-management might not apply.¹⁰ Three important reviews on self-management in different conditions have a common denominator: integrating recommendations in one's daily life is probably the biggest challenge in self-management.^{11–13} The authors describe that 'living a life and living an illness'¹² are two different things, and developing a daily self-management routine as a response to lifestyle changes¹¹ is considered to facilitate self-management.¹³ They suggest that patients need scheduling and prioritisation skills in their familial and societal roles, such as work or special occasions like holidays and vacations.^{11 13} To better conceptualise the important challenge of developing a self-management routine, it is of significant value to understand the underlying factors that affect such process in people living with chronic conditions. Literature offers valuable evidence on general aspects that influence self-management, from personal factors such as one's emotional needs and health beliefs,^{14 15} to more logistical ones like access and financial constraints.^{11 13 16} Notwithstanding the important contribution, we believe that in order to grasp the complexities of self-management routines there is a need to synthesise the evidence of patients' lived experience on closer lens. Instead of the existing description of self-management within the frame of concepts like barriers and facilitators, we believe that a more personal approach should be presented. Van de Velde *et al*² said that self-management is not a task that has an end point, on the opposite, it is a lifetime task that is based on how patients see their own problems in their own daily lives; self-management will look different for each person, depending on their skills.² Therefore, with this review, we want to describe the performance of self-management routines within daily settings in people living with chronic conditions with the aim of identifying factors that challenge its integration in daily life. To reach the aim of our study, we chose to follow a scoping review methodology. Since our 'phenomena of interest'—the performance of self-management routines—is very broad, we deem this methodology to be appropriate for scoping the range of the available evidence.¹⁷ By summarising different research findings in qualitative research, this scoping review will allow us to identify possible research gaps and to make recommendations for future research in the field of patient education.

METHODS

To reach the aforementioned objective, we followed Arksey and O'Malley's methodology for conducting a scoping review.¹⁸ We adopted the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews (PRISMA-ScR) checklist for reporting the steps (see online supplemental material 1, PRISMA-ScR Checklist).¹⁹

Identifying the research question

The review was guided by the following questions:

RQ1: What are the factors that challenge the performance of self-management routines within daily settings in people living with chronic conditions?

RQ2: How do these factors influence this process?

Inclusion and exclusion criteria

We based the selection of studies on the following eligibility criteria: (1) qualitative studies on self-management experience, (2) in English, (3) adult participants, (4) original and peer-reviewed and (5) depicting the performance of self-management activities in one's own environment. We excluded studies that focus on self-management interventions, portraying challenges related to an individual's personal attribute such as age, gender and origins. Furthermore, we excluded studies looking at self-management in chronic condition, such as substance abuse, central nervous system disease, and insomnia, given that they can be particularly different in these population due to affected cognitive function²⁰ and involve specific requirements for self-management, such as more medication dependency.²¹ However, is worth mentioning that we included those multimorbidity studies that look at these conditions among others. Lastly, we excluded articles exploring self-management of HIV/AIDS or cancer, given that these conditions are characterised by a great amount of unpredictability and considered life-threatening.²² They require complex therapeutic routines in closer collaboration with health professionals because of demanding and frequent monitoring and there is an extensive use of health services like palliative care for symptom control.^{23 24}

Search for relevant studies

In February 2022, we searched PubMed, Web of Science, CINAHL and PsycINFO for relevant articles using a group of keywords that reflect our objective and research question as shown in table 1. We combined the keywords using Boolean operators and truncations. A preliminary screening of the literature in these databases revealed that most of the research in the field has been done in the new millennium. Therefore, a time limit was placed, starting from the year 2000.

Selection of sources of evidence

One reviewer carried out the search through electronic databases and kept a record of the searches. The identified records were exported into EndNote and duplicates were removed. The screening of the articles was performed in two levels. In the first level of screening, two reviewers applied the inclusion and exclusion criteria to all titles and abstracts independently for study eligibility. Discrepancies were resolved by consensus or the participation of a third reviewer. For the second level of screening, two reviewers independently performed a full-text screening of a sample of the articles against the inclusion and exclusion criteria (ie, 'depicting the performance of self-management activities in one's own environment' and 'portraying challenges related to an individual's personal

Table 1 Search string combination of keywords

Database	Search string combination
PubMed	((("chronic disease" OR "chronic condition" OR "chronic illness" OR "complex chronic condition" OR "complex chronic disease" OR "complex chronic illness"[Title/Abstract] OR multimorbid*[Title/Abstract] OR "multiple diseases"[Title/Abstract] OR "multiple conditions"[Title/Abstract] OR "multiple illnesses"[Title/Abstract] OR comorbid*[Title/Abstract]) AND ("self management"[Title/Abstract] OR "self efficacy"[Title/Abstract] OR "self care"[Title/Abstract] OR "health behaviour"[Title/Abstract])) AND (adapt*[Title/Abstract] OR intergrat*[Title/Abstract] OR adjust*[Title/Abstract] OR transit*[Title/Abstract] OR "lived experience"[Title/Abstract] OR sustain*[Title/Abstract] OR balance*[Title/Abstract] OR maintain*[Title/Abstract] OR learn*[Title/Abstract] OR "problem solving"[Title/Abstract] OR "decision making"[Title/Abstract]))
Cinahl Complete	TX ("chronic disease" OR "chronic condition" OR "chronic illness" OR "complex chronic condition" OR "complex chronic disease" OR "complex chronic illness" OR multimorbid* OR "multiple diseases" OR "multiple conditions" OR "multiple illnesses" OR comorbid*) AND AB ("self management" OR "self efficacy" OR "self care" OR "health behaviour") AND AB (adapt* OR intergrat* OR adjust* OR transit* OR "lived experience" OR sustain* OR balance* OR maintain* OR learn* OR "problem solving" OR "decision making")
Web of Science	"chronic disease" OR "chronic condition" OR "chronic illness" OR "complex chronic condition" OR "complex chronic disease" OR "complex chronic illness" OR multimorbid* OR "multiple diseases" OR "multiple conditions" OR "multiple illnesses" OR comorbid* (Abstract) and "self management" OR "self efficacy" OR "self care" OR "health behaviour" (Abstract) and adapt* OR intergrat* OR adjust* OR transit* OR "lived experience" OR sustain* OR balance* OR maintain* OR learn* OR "problem solving" OR "decision making" (All Fields) and 2000 or 2001 or 2002 or 2003 or 2004 or 2005 or 2006 or 2007 or 2008 or 2009 or 2010 or 2011 or 2012 or 2013 or 2014 or 2015 or 2016 or 2017 or 2018 or 2019 or 2020 or 2021 or 2022 (Publication Years) and English (Languages)
PsycInfo	((("chronic disease" or "chronic condition" or "chronic illness" or "complex chronic condition" or "complex chronic disease" or "complex chronic illness" or multimorbid* or "multiple diseases" or "multiple conditions" or "multiple illnesses" or comorbid*) and ("self management" or "self efficacy" or "self care" or "health behaviour")).ab. and (adapt* or intergrat* or adjust* or transit* or "lived experience" or sustain* or balance* or maintain* or learn* or "problem solving" or "decision making").af.

attribute such as age, gender and origins') to determine the degree of consistency in the individual assessment. Any disagreements were resolved through discussions with the third reviewer. After reaching an agreement one reviewer screened the full texts for inclusion and exclusion criteria. (see online supplemental figure 1 PRISMA flow chart).

Charting the data

Two reviewers prepared a standardised table to extract relevant information from eligible articles. Data extraction was conducted independently by the same reviewers. Online supplemental table 1 includes the primary author, year of publication, country, sample size, place of recruitment, type of disease, study design, self-management activity/recommendation and aim of study. Online supplemental table 2 summarised the extracts from the included studies and initial codes. When conducting the database research, we did not include the keywords 'challenge' or 'barrier', neither did we discriminate according to the study aim when selecting eligible studies. Therefore, findings of the included studies did not necessarily report only on challenges of the performing self-management routines. For this reason, only those parts of the findings where challenges in one's environment and daily routines are mentioned, were taken in consideration. Furthermore, the reviewers agreed to extract only the author's

own interpretation of the data accompanied by author's chosen quotes for illustration.

Collating, summarising and reporting the results

For this stage of the review, we followed Braun and Clarke's methodology for inductive thematic analysis, based on the theoretical framework of a realist account.²⁵ In the first stage of data extraction, we became familiar with the results of each included study, by repeatedly reading the content in depth. In this phase, one reviewer started taking notes on possible codes. The same key findings could contribute in more than one code and theme. After generating the initial codes, two reviewers went through the process of generating themes and subthemes, through continual revisions and definitions of themes as seen in online supplemental table 3. Any discrepancy was resolved by the participation of a third reviewer. For the final phase, we produced the report by following an analysis of the challenges of performing self-management routines within one's daily environment guided by our research question: what are challenges of keeping up with recommendations of self-management regardless of the setting or daily activities of the participants?

Patient and public involvement

None.

RESULTS

Study characteristics

After screening the abstracts of 9360 articles, 717 were included for full-text screening. Of these, 694 studies were deemed ineligible. Ultimately, 22 articles in total were included for synthesis,^{26–47} as illustrated in online supplemental figure 1. The studies were conducted between 2001⁴² and 2021.⁴³ The majority (n=9) are from the USA^{27 29 33–36 38 41 44}; there are three from Australia,^{28 31 46} three from Canada,^{30 40 42} two from Sweden^{26 32} and one each from Switzerland,⁴⁷ the UK,³⁷ Malawi,³⁹ the Netherlands,⁴⁵ and Malaysia.⁴³ There are 20 qualitative studies^{26–34 36 37 39–47} and 2 mixed-methods studies^{35 38} (from which only the qualitative data were extracted) represent more than 690 participants. Articles cover a wide range of conditions including diabetes (n=12),^{26 28–30 32 36 37 39 42 44–46} cardiovascular conditions (n=11),^{26 28–31 33 36 38 44–46} lung conditions (n=7),^{28 30 31 35 36 41 43} rheumatic diseases (n=5),^{26 29 30 36 45} kidney disease (n=4),^{26 27 45 46} spinal cord injury (n=2),^{40 47} cancer (n=2),^{29 45} depression (n=2),^{29 36} inflammatory bowel disease (n=1),²⁶ multiple sclerosis (n=1),²⁶ back pain or sciatica (n=1),²⁹ obesity (n=1),³⁰ glaucoma (n=1),⁴⁵ hearing disability (n=1),⁴⁵ vision problems (n=1),⁴⁵ tuberculosis (n=1),⁴⁵ immune disease (n=1)⁴⁵ and gastric bypass surgery (n=1).⁴⁵ Twenty-one studies used a cross-sectional design,^{27–47} and only one study followed a longitudinal approach for data collection and analysis.²⁶ Most of the studies aim at describing the experience, understanding and performance of self-management (n=9).^{28 30 33 37–39 41 43} Six studies aim at exploring facilitators and barriers of self-management (n=6).^{27 29 31 36 40 44} Four studies explore issues and challenges in self-management.^{32 34 35 45} Two studies explore decision-making and adaptation styles in self-management^{42 47} and one investigates the patterns of self-management behaviours over time.²⁶

Thematic analysis

The synthesis of results yielded two main overarching themes: the Environment support with three subthemes: family and cultural norms, health professionals and guiding communication, and society and chronic disease perceptions; and the Comprehension gap with two subthemes: reading the body and applying information.

Environment support

The first theme describes that the way patients make decisions about self-management and prioritise on a daily basis, could be influenced by their relationship with family and society, and information exchange with health professionals.

Family and cultural norms

The first subtheme involves cultural norms and gender roles within a family and explains different perceptions of personal responsibility in disease self-management. Given that most of a person's daily disease management is spent at home, it is not unexpected that patients feel

compelled to incorporate their recommendations as best they can within their family's traditions and expectations.^{27 33 36 37 39 40 46} While some of them highlight that they receive unconditional support,^{27 36} others emphasise that sometimes gender roles (eg, spouses and mothers) within a family could jeopardise self-care.^{36 37 46} They feel the pressure of having to choose and prioritise^{27 33 39 46} between their self-management routines or family needs⁴⁶: 'a participant stated: I have three (grown) men to look after and it influences my medicine taking. Other participants cared for sick family members, which was an added stress, and prioritised their care over their own at times'.⁴⁶

Health professionals and guiding communication

The second subtheme illustrates the support of healthcare professionals through instructions on practical aspects of self-management routines. Patients believe that it is crucial to have the right professional guidance in order to understand the 'larger picture' of the condition.^{27 29 34 36 38 42 45 47} Some patients advocated for medical paternalism and needed an active support for every problem and decisional process in their self-management.^{45 47} More independent patients reported receiving fragmented information^{27 34} in a hurried encounter with their physicians³⁶: 'participants reported feeling "rushed" through doctor visits: 'The doctor doesn't have time to be thorough'.^{36 43} They also believed that advice was not based on the reality^{29 38 42} of the patient's environment³⁸: 'cognitive artefacts were ill suited for older users, their experiences, mental models, limitations and daily routines'.³⁸ As a result, they felt ill equipped to deal with unanticipated situations^{36 42} and make educated decisions on how to deal with them⁴²: 'practitioners who give information irrelevant to their unique situations impair the ability to use that information'.⁴² Finally, this led to a loss of faith in the health professionals, which caused patients to experience feelings of incompetence and disempowerment.^{29 42}

Society and chronic disease perceptions

The third theme describes general societal expectations towards people living with a chronic condition that have to constantly self-manage. Patients describe feeling as though they are not leading an enjoyable life despite their disease^{30 39 43} until they were confident enough to follow instructions in various settings⁴³: 'playing football were identified as essential activities in embodying health identities...for these participants, using an inhaler before a game or during a match demonstrated 'weakness' and invited unwanted social reactions'.⁴³ Stigmatising events like distancing attitudes³⁰ or unpleasant reactions from friends or peers,⁴³ inevitably influenced self-management and brought out feelings of isolation³⁰: 'My cousin has a cabin in the woods 2 hours away and doesn't dare invite me anymore because of my health'.³⁰ In general, participants in this sample preferred to do things alone rather than to deal with the pressure of spending time with others'.³⁰

Comprehension gap

The second theme describes that a patients' ability to plan and schedule self-management recommendations around work or social events seems to be influenced by their understanding of the disease and body cues.

Reading the body

This theme describes the difficulties that patients experience in recognising deviations from standard physiological norms and how it challenges their ability plan self-management in different situations.^{26 28 31 32 34 35 41 44} This can often make it difficult for them to apply self-management recommendations in the best way possible^{31 32 34 44} in order to reach the desired result⁴⁴: 'Knowledge gaps included misunderstandings about what constitutes the appropriate frequency, intensity and duration of physical activity and how to incorporate dietary changes into their lifestyle'.⁴⁴ Patients also had difficulty leading normal lives with self-management because they were unable to comprehend and predict how their bodies could respond to outside stimuli.^{32 34 35 41} A typical example was: 'one challenge was to understand.... how blood glucose levels and daily routines affect each other'.³² Sometimes family members could provide help in identifying and reacting to certain cues²⁸; in more independent cases these knowledge gaps could make patients clueless of the fact that a good life can be achieved with proper self-management⁴¹: 'Patients had accepted a level of restricted freedom of movement as a result of asthma and did not recognise the potential quality of life he or she could achieve with greater asthma control'.⁴¹

Applying information

The final subtheme illustrates how, even when one has the knowledge, the ability to apply that knowledge to one's specific situation and self-manage one's condition is what requires their attention.^{29 32 36} Patients faced difficulties in exercising planning and scheduling skills to fit self-management activities around work or social engagements.^{29 32} Additionally, there were patients that tended to give up their recommendations because of poor information evaluating skills like in this example³²: 'One participant...assumed that walking or climbing stairs at work only affected blood cholesterol values...He assumed that physical activity needs to be exercised in another way for maximum health benefit'.³²

DISCUSSION AND FURTHER RESEARCH

Discussion

This review aimed to describe the routine of self-management in patients with chronic conditions within their own environment and it demonstrates their difficulties in reading body signals and cues and applying knowledge to specific circumstances. Our analysis suggests that patients are in need of better training and information coordination that would support their ability to understand; to react accordingly; to make plans and predictions

in self-management regardless of the environment. Interestingly, there is a two-dimensional knowledge gap among patients. On the one hand, they are unsure whether the advice of medical professionals can be implemented uniformly in all circumstances. On the other hand, they do not know whether the information coming from their bodies can be predictable enough for them to feel confident and react appropriately.

Our findings are consistent with other reviews on different chronic conditions^{12 13} in describing the need for flexibility and creativity in order to regulate and keep the same self-management routines in a changing context. Our results extend on that knowledge by highlighting that what is actually needed is the 'know-how' approach in trainings and education, which can better assist the creation of a routine and a life with self-management. We did not look into specific self-management education interventions and whether they cover all the necessary skills need in self-management. Yet we know that skills like problem-solving interventions have shown their contribution on self-management maintenance over time in complex conditions like diabetes,⁴⁸ depression⁴⁹ or spinal cord injury.⁵⁰ More studies should explore methods used by health professionals to build personalised profiles, and whether they use skill assessment tools for their patients with chronic conditions. Additionally, we explored only the views of patients. However, literature shows that the way family members experience chronic conditions⁵¹⁻⁵⁴ or what is considered for health professionals the right way to solve unexpected situations in daily routines^{55 56} often is very different from patients' perspective. Accounts on the lived-experience of self-management of all actors involved would add to our data.

Important research efforts have contributed on further conceptualisation of self-management integration, by developed models that explain its trajectory by different phases and turning points.^{57 58} Patients use strategy like developing self-awareness of the ways the body responds to certain stimuli or situations through trial and error⁵⁹⁻⁶¹ as well as constantly clarifying the information they receive.⁶²⁻⁶⁴ This review identified one longitudinal study exploring different patterns of chronic illness self-management.²⁶ To better grasp the developmental character of self-management routines, more longitudinal evidence is required on strategies and learning needs throughout different stages.^{65 66}

Strengths and limitations

Our review has some important strengths to be highlighted. First, the methodology followed for this scoping review allowed for assessing an extensive body of literature, across different study aims, different conditions and populations. This made possible to identify important gaps for further research, with longitudinal qualitative study design in self-management being one of them. Another strength was the use of the standards for conducting and reporting reviews, and the employment of a rigorous thematic analysis process which involved

independent analysis by two researchers and several critical discussion meetings with all reviewers. Finally, to our knowledge, this is the first scoping review that explores self-management solely from the context of creating a routine within one's daily setting, giving contribution to the existing literature.

Notwithstanding the above, the study had some limitations that should be acknowledged. First, a quality appraisal of the reviewed studies was not undertaken. The synthesis, however, did not aim to identify the impact of what has been studied or evaluate the strength of the evidence available^{17 67}; instead, the aim was to provide an overview that is as comprehensive as possible of aspects of self-management routines in daily settings. The second limitation is the potential exclusion of relevant studies, as a result of the conceptualisation of the search strategy. We may have neglected some aspects of the routines of self-management, since there is no clear conceptualisation in the literature and we only explored a limited number of concepts linked to it. However, the large number of screened articles and engagement with the existing literature suggest that the results reflect the most important aspects that were intended to be explored in this review. Almost all reviewed articles were conducted in Western countries. Further exploration of this topic should be undertaken to determine particularities in different countries and cultures.⁶⁸ This research entailed synthesising evidence on a broad range of chronic diseases and self-management activities. Although it can offer a strong basis for generalisation, more in-depth research on individual conditions or self-management activities and recommendations should be carried out.

CONCLUSION

The integration of self-management requirements in a daily routine is affected by the patients' inability to apply disease knowledge in different context and by the challenge of understanding body symptoms and predicting body reactions in advance. Health professionals could benefit from using skill assessment tools for their patients, in order to create more comprehensive and personalised interventions for patient education in chronic condition self-management.

Twitter Enxhi Qama @enxhiqama

Contributors All authors contributed to the conceptualisation of the study. ND and SR secured funds for the study. EQ and ND designed the study. ND and SR collected data, carried out the analysis and interpreted the data. EQ collected data, carried out the analysis, interpreted the data and prepared the original draft of the manuscript. ND supervised the project. All authors contributed important intellectual content during manuscript drafting and revisions. They also read and approved the final manuscript. EQ acted as guarantor.

Funding The work presented in this paper has been funded by the Swiss National Science Foundation (www.snf.ch; Grant No. 10001C_200520).

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Our study did not require an ethical board approval because it did not contain human or animal trials.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as online supplemental information.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Enxhi Qama <http://orcid.org/0000-0002-9466-3379>

REFERENCES

- 1 Richard AA, Shea K. Delineation of self-care and associated concepts. *J Nurs Scholarsh* 2011;43:255–64.
- 2 Van de Velde D, De Zutter F, Satink T, et al. Delineating the concept of self-management in chronic conditions: a concept analysis. *BMJ Open* 2019;9:e027775.
- 3 Goodman RA, Posner SF, Huang ES, et al. Defining and measuring chronic conditions: imperatives for research, policy, program, and practice. *Prev Chronic Dis* 2013;10.
- 4 O'Halloran J, Miller GC, Britt H. Defining chronic conditions for primary care with ICD-10. *Fam Pract* 2004;21:381–6.
- 5 Shaul MP. From early twinges to mastery: the process of adjustment in living with rheumatoid arthritis. *Arthritis Care Res* 1995;8:290–7.
- 6 Schulman-Green D, Jaser S, Martin F, et al. Processes of self-management in chronic illness. *J Nurs Scholarsh* 2012;44:136–44.
- 7 Robinson CA. Managing life with a chronic condition: the story of normalization. *Qual Health Res* 1993;3:6–28.
- 8 Kwasnicka D, Dombrowski SU, White M, et al. Theoretical explanations for maintenance of behaviour change: a systematic review of behaviour theories. *Health Psychol Rev* 2016;10:277–96.
- 9 Sniehotta FF, Schwarzer R, Scholz U, et al. Action planning and coping planning for long-term lifestyle change: theory and assessment. *Eur J Soc Psychol* 2005;35:565–76.
- 10 Mackey LM, Doody C, Werner EL, et al. Self-management skills in chronic disease management: what role does health literacy have? *Med Decis Making* 2016;36:741–59.
- 11 Koch G, Wakefield BJ, Wakefield DS. Barriers and facilitators to managing multiple chronic conditions: a systematic literature review. *West J Nurs Res* 2015;37:498–516.
- 12 Liddy C, Blazkho V, Mill K. Challenges of self-management when living with multiple chronic conditions: systematic review of the qualitative literature. *Can Fam Physician* 2014;60:1123–33.
- 13 Schulman-Green D, Jaser SS, Park C, et al. A metasynthesis of factors affecting self-management of chronic illness. *J Adv Nurs* 2016;72:1469–89.
- 14 Russell S, Ogunbayo OJ, Newham JJ, et al. Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals. *NPJ Prim Care Respir Med* 2018;28:1–13.
- 15 Siabani S, Leeder SR, Davidson PM. Barriers and facilitators to self-care in chronic heart failure: a meta-synthesis of qualitative studies. *Springerplus* 2013;2:320.
- 16 Miles C, Arden-Close E, Thomas M, et al. Barriers and facilitators of effective self-management in asthma: systematic review and thematic synthesis of patient and healthcare professional views. *NPJ Prim Care Respir Med* 2017;27:57.
- 17 Peters MDJ, Godfrey CM, Khalil H, et al. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015;13:141–6.
- 18 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.

- 19 Tricco AC, Lillie E, Zarin W, *et al.* PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018;169:467–73.
- 20 Botvin GJ, Griffin KW, Scheier LM. Developmental trajectories of self-management skills and adolescent substance use. *Salud Drogas* 2009;9:15–37.
- 21 Trivedi MH, Lin EHB, Katon WJ. Consensus recommendations for improving adherence, self-management, and outcomes in patients with depression. *CNS Spectr* 2007;12:1–27.
- 22 Chattopadhyay S, Karlsson J, Mañas A, *et al.* Evolutionary unpredictability in cancer model system. *bioRxiv* 2022.
- 23 Mansky PJ, Wallerstedt DB. Complementary medicine in palliative care and cancer symptom management. *Cancer J* 2006;12:425–31.
- 24 Harding R. Palliative care as an essential component of the HIV care continuum. *Lancet HIV* 2018;5:e524–30.
- 25 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- 26 Auduly Åsa. The over time development of chronic illness self-management patterns: a longitudinal qualitative study. *BMC Public Health* 2013;13:452.
- 27 Bowling CB, Vandenberg AE, Phillips LS, *et al.* Older patients' perspectives on managing complexity in CKD self-management. *Clin J Am Soc Nephrol* 2017;12:635–43.
- 28 Corcoran KJ, Jowsey T, Leeder SR. One size does not fit all: the different experiences of those with chronic heart failure, type 2 diabetes and chronic obstructive pulmonary disease. *Aust Health Rev* 2013;37:19–25.
- 29 Dixon A, Hibbard J, Tusler M. How do people with different levels of activation self-manage their chronic conditions? *Patient* 2009;2:257–68.
- 30 Duguay C, Gallagher F, Fortin M. The experience of adults with multimorbidity: a qualitative study. *J Comorb* 2014;4:11–21.
- 31 Fuller BG, Stewart Williams JA, Byles JE. Active living—the perception of older people with chronic conditions. *Chronic Illn* 2010;6:294–305.
- 32 Gardsten C, Blomqvist K, Rask M, *et al.* Challenges in everyday life among recently diagnosed and more experienced adults with type 2 diabetes: a multistage focus group study. *J Clin Nurs* 2018;27:3666–78.
- 33 Gary R. Self-care practices in women with diastolic heart failure. *Heart Lung* 2006;35:9–19.
- 34 Haverhals LM, Lee CA, Siek KA, *et al.* Older adults with multimorbidity: medication management processes and design implications for personal health applications. *J Med Internet Res* 2011;13:e44.
- 35 Janevic MR, Ellis KR, Sanders GM, *et al.* Self-management of multiple chronic conditions among African American women with asthma: a qualitative study. *J Asthma* 2014;51:243–52.
- 36 Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. *Patient Educ Couns* 2005;57:300–7.
- 37 Majeed-Ariss R, Jackson C, Knapp P, *et al.* British-Pakistani women's perspectives of diabetes self-management: the role of identity. *J Clin Nurs* 2015;24:2571–80.
- 38 Mickelson RS, Willis M, Holden RJ. Medication-related cognitive artifacts used by older adults with heart failure. *Health Policy Technol* 2015;4:387–98.
- 39 Mphwanthe G, Carolan M, Earnesty D, *et al.* Perceived barriers and facilitators to diet and physical activity among adults diagnosed with type 2 diabetes in Malawi. *Glob Public Health* 2021;16:469–84.
- 40 Munce SEP, Webster F, Fehlings MG, *et al.* Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. *BMC Neurol* 2014;14:48.
- 41 O'Connor R, Martynenko M, Gagnon M, *et al.* A qualitative investigation of the impact of asthma and self-management strategies among older adults. *J Asthma* 2017;54:39–45.
- 42 Paterson B. Myth of empowerment in chronic illness. *J Adv Nurs* 2001;34:574–81.
- 43 Salim H, Young I, Lee PY, *et al.* Insights into how Malaysian adults with limited health literacy self-manage and live with asthma: a Photovoice qualitative study. Health expectations : an international journal of public participation in health care and health policy. *Health Expect* 2021.
- 44 Steinman L, Heang H, van Pelt M, *et al.* Facilitators and barriers to chronic disease self-management and mobile health interventions for people living with diabetes and hypertension in Cambodia: qualitative study. *JMIR Mhealth Uhealth* 2020;8:e13536.
- 45 van de Bovenkamp HM, Dwarswaard J. The complexity of shaping self-management in daily practice. *Health Expect* 2017;20:952–60.
- 46 Williams A, Manias E, Cross W, *et al.* Motivational interviewing to explore culturally and linguistically diverse people's comorbidity medication self-efficacy. *J Clin Nurs* 2015;24:1269–79.
- 47 Zanini C, Brach M, Lustenberger N, *et al.* Engaging in the prevention of pressure injuries in spinal cord injury: a qualitative study of community-dwelling individuals' different styles of prevention in Switzerland. *J Spinal Cord Med* 2020;43:247–56.
- 48 Fitzpatrick SL, Schumann KP, Hill-Briggs F. Problem solving interventions for diabetes self-management and control: a systematic review of the literature. *Diabetes Res Clin Pract* 2013;100:145–61.
- 49 Gellis ZD, Kenaley B. Problem-solving therapy for depression in adults: a systematic review. In: *Research on social work practice*, 182008: 117–31.
- 50 Elliott TR, Shewchuk RM, Richards JS. Caregiver social problem-solving abilities and family member adjustment to recent-onset physical disability. *Rehabil Psychol* 1999;44:104–23.
- 51 Crespo C, Santos S, Canavarro MC, *et al.* Family routines and rituals in the context of chronic conditions: a review. *Int J Psychol* 2013;48:729–46.
- 52 Gallant MP, Spitze GD, Prohaska TR. Help or hindrance? How family and friends influence chronic illness self-management among older adults. *Res Aging* 2007;29:375–409.
- 53 Satink T, Josephsson S, Zajec J, *et al.* Negotiating role management through everyday activities: narratives in action of two stroke survivors and their spouses. *Disabil Rehabil* 2016;38:2354–64.
- 54 Whitehead L, Jacob E, Towell A, *et al.* The role of the family in supporting the self-management of chronic conditions: a qualitative systematic review. *J Clin Nurs* 2018;27:22–30.
- 55 Anderson RM. Patient empowerment and the traditional medical model. A case of irreconcilable differences? *Diabetes Care* 1995;18:412–5.
- 56 Bodenheimer T, Lorig K, Holman H, *et al.* Patient self-management of chronic disease in primary care. *JAMA* 2002;288:2469–75.
- 57 Auduly A, Asplund K, Norbergh K-G. The integration of chronic illness self-management. *Qual Health Res* 2012;22:332–45.
- 58 Hörnsten Åsa, Jutterström L, Auduly Åsa, *et al.* A model of integration of illness and self-management in type 2 diabetes. *J Nurs Healthc Chronic Illn* 2011;3:41–51.
- 59 Deshaies K, Hernandez CA. Integration: a phenomenon to explore in chronic nonmalignant pain (CNP). *Pain Manag Nurs* 2011;12:2–14.
- 60 Whittemore R, Chase SK, Mandle CL, *et al.* Lifestyle change in type 2 diabetes: a process model. *Nurs Res* 2002;51:18–25.
- 61 Diviani N, Obrenovic J, Montoya CL, *et al.* Disentangling health information appraisal competence: results from an interdisciplinary scoping review and online consultation among Swiss stakeholders. *PLoS One* 2020;15:e0235474.
- 62 Mickelson RS, Unertl KM, Holden RJ. Medication management: the Macrocognitive workflow of older adults with heart failure. *JMIR Hum Factors* 2016;3:e27.
- 63 Dickson VV, Buck H, Riegel B. Multiple comorbid conditions challenge heart failure self-care by decreasing self-efficacy. *Nurs Res* 2013;62:2–9.
- 64 Vest JR, Gamm LD. Health information exchange: persistent challenges and new strategies. *J Am Med Inform Assoc* 2010;17:288–94.
- 65 Hermanowicz JC. The longitudinal qualitative interview. *Qual Sociol* 2013;36:189–208.
- 66 Saldaña J. *Longitudinal qualitative research: analyzing change through time*. Rowman Altamira, 2003.
- 67 Lucas PJ, Baird J, Arai L, *et al.* Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Med Res Methodol* 2007;7:1–7.
- 68 Paterson BL, Russell C, Thorne S. Critical analysis of everyday self-care decision making in chronic illness. *J Adv Nurs* 2001;35:335–41.