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

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 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. 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. The authors describe that ‘living a life and living an illness’ are two different things, and developing a daily self-management routine as a response to lifestyle changes is considered to facilitate self-management. 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. 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, to more logistical ones like access and financial constraints. 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. 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. 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 describing the range of the available evidence. 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. 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).

**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 this population due to affected cognitive function and involve specific requirements for self-management, such as more medication dependency. However, it 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. 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.

**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
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.

<table>
<thead>
<tr>
<th>Database</th>
<th>Search string combination</th>
</tr>
</thead>
<tbody>
<tr>
<td>PubMed</td>
<td>(&quot;chronic disease&quot; OR &quot;chronic condition&quot; OR &quot;chronic illness&quot; OR &quot;complex chronic condition&quot; OR &quot;complex chronic disease&quot; OR &quot;complex chronic illness&quot; [Title/Abstract] OR &quot;multiple diseases&quot; [Title/Abstract] OR &quot;multiple conditions&quot; [Title/Abstract] OR &quot;multiple illnesses&quot; [Title/Abstract] OR comorbid&quot; [Title/Abstract]) AND (&quot;self management&quot; [Title/Abstract] OR &quot;self efficacy&quot; [Title/Abstract] OR &quot;self care&quot; [Title/Abstract] OR &quot;health behaviour&quot; [Title/Abstract]) AND (adapt OR intergrat OR adjust OR transit OR &quot;lived experience&quot; OR sustain OR balance OR maintain OR learn OR &quot;problem solving&quot; OR &quot;decision making&quot;) [Title/Abstract]</td>
</tr>
<tr>
<td>Cinahl Complete</td>
<td>TX (&quot;chronic disease&quot; OR &quot;chronic condition&quot; OR &quot;chronic illness&quot; OR &quot;complex chronic condition&quot; OR &quot;complex chronic disease&quot; OR &quot;complex chronic illness&quot; OR multimorbid OR &quot;multiple diseases&quot; OR &quot;multiple conditions&quot; OR &quot;multiple illnesses&quot; OR comorbid&quot;) AND AB (&quot;self management&quot; OR &quot;self efficacy&quot; OR &quot;self care&quot; OR &quot;health behaviour&quot;) AND AB (adapt OR intergrat OR adjust OR transit OR &quot;lived experience&quot; OR sustain OR balance OR maintain OR learn OR &quot;problem solving&quot; OR &quot;decision making&quot;)</td>
</tr>
<tr>
<td>Web of Science</td>
<td>&quot;chronic disease&quot; OR &quot;chronic condition&quot; OR &quot;chronic illness&quot; OR &quot;complex chronic condition&quot; OR &quot;complex chronic disease&quot; OR &quot;complex chronic illness&quot; OR multimorbid OR &quot;multiple diseases&quot; OR &quot;multiple conditions&quot; OR &quot;multiple illnesses&quot; 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)</td>
</tr>
<tr>
<td>PsycInfo</td>
<td>(“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.</td>
</tr>
</tbody>
</table>
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 200126 and 2021.33 The majority (n=9) are from the USA,27 29–33 36 41 44; there are three from Australia,28 31 46 three from Canada,30 40 42 two from Sweden26 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 36–39 44–47 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),26 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 crossed-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),26 33 35 37–39 41 43 Six studies aim at exploring facilitators and barriers of self-management (n=6).27 29 31 36 40 44 Fours studies explore issues and challenges in self-management.32 34 35 45 Two studies explore decision-making and adaptation styles in self-management42 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,47 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 prioritise27 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 42 45 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 information27 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 45 They also believed that advice was not based on the reality39 42 of the patient’s environment36; ‘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 situations36 42 and make educated decisions on how to deal with them42; ‘practitioners who gave 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 disease30 39 45 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’.44 Stigmatising events like distancing attitudes30 or unpleasant reactions from friends or peers45 inevitably influenced self-management and brought about 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 possible29 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 cues30; 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’.32

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 conditions12 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 at 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 routines55 56 is often 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.37 38 Patients use strategy like developing self-awareness of the ways the body responds to certain stimuli or situations through trial and error39–41 as well as constantly clarifying the information they receive.52–64 This review identified one longitudinal study exploring different patterns of chronic illness self-management.20 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; 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. 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 contexts 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 Enshi Qama @enhiqama

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, 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 Enshi Qama http://orcid.org/0000-0002-9466-3379

REFERENCES


## Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

<table>
<thead>
<tr>
<th>SECTION</th>
<th>ITEM</th>
<th>PRISMA-ScR CHECKLIST ITEM</th>
<th>REPORTED ON PAGE #</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TITLE</strong></td>
<td>Title</td>
<td>Identify the report as a scoping review.</td>
<td>2-3</td>
</tr>
<tr>
<td><strong>ABSTRACT</strong></td>
<td>Structured summary</td>
<td>Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.</td>
<td>4-5</td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td>Rationale</td>
<td>Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.</td>
<td>5</td>
</tr>
<tr>
<td><strong>METHODS</strong></td>
<td>Objectives</td>
<td>Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.</td>
<td>6</td>
</tr>
<tr>
<td>Protocol and registration</td>
<td>5</td>
<td>Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.</td>
<td>N/A</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>6</td>
<td>Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.</td>
<td>6</td>
</tr>
<tr>
<td>Information sources*</td>
<td>7</td>
<td>Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.</td>
<td>6-7</td>
</tr>
<tr>
<td>Search</td>
<td>8</td>
<td>Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.</td>
<td>7, Table 1</td>
</tr>
<tr>
<td>Selection of sources of evidence†</td>
<td>9</td>
<td>State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.</td>
<td>7-8, see Supplementary Table 1, Supplementary Table 2, N/A</td>
</tr>
<tr>
<td>Data charting process‡</td>
<td>10</td>
<td>Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.</td>
<td>8</td>
</tr>
<tr>
<td>Data items</td>
<td>11</td>
<td>List and define all variables for which data were sought and any assumptions and simplifications made.</td>
<td>8</td>
</tr>
<tr>
<td>Critical appraisal of individual sources of evidence§</td>
<td>12</td>
<td>If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).</td>
<td>8</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>13</td>
<td>Describe the methods of handling and summarizing the data that were charted.</td>
<td>14, 1</td>
</tr>
<tr>
<td>SECTION</td>
<td>ITEM</td>
<td>PRISMA-ScR CHECKLIST ITEM</td>
<td>REPORTED ON PAGE #</td>
</tr>
<tr>
<td>---------------</td>
<td>------</td>
<td>-------------------------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>RESULTS</td>
<td>14</td>
<td>Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.</td>
<td>Supplementary Figure 1</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>For each source of evidence, present characteristics for which data were charted and provide the citations.</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>If done, present data on critical appraisal of included sources of evidence (see item 12).</td>
<td>Supplementary Table 3</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.</td>
<td>Table 3</td>
</tr>
<tr>
<td></td>
<td>18</td>
<td>Summarize and/or present the charting results as they relate to the review questions and objectives.</td>
<td>23-28</td>
</tr>
<tr>
<td>DISCUSSION</td>
<td>19</td>
<td>Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.</td>
<td>14-18</td>
</tr>
<tr>
<td></td>
<td>20</td>
<td>Discuss the limitations of the scoping review process.</td>
<td>20-21</td>
</tr>
<tr>
<td></td>
<td>21</td>
<td>Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.</td>
<td>21</td>
</tr>
<tr>
<td>FUNDING</td>
<td>22</td>
<td>Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.</td>
<td>21</td>
</tr>
</tbody>
</table>

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

Where sources of evidence (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with information sources (see first footnote).

† The frameworks byArksey and O'Malley (6) andLevac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

‡ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

Supplementary Figure 1. Prisma flow diagram

Identification

- PubMed: n = 2882
- Cinahl: n = 2681
- Web of Science: n = 1880
- Psycinfo: n = 1917

Duplicates: n = 3635

Screening

- Title and abstract screening: n = 5725
- Records excluded: n = 5008

Eligibility

- Full-text screening: n = 717

Included

- Articles included in qualitative synthesis: n = 22
- Articles included in quantitative synthesis (meta-analysis): n = n/a

Full text records excluded: n = 694

- Not reflecting challenges of SM (n = 207)
- Not-original data (n = 182)
- Quantitative research (n = 91)
- Not about self-management (n = 79)
- Conditions with specific requirements (n = 56)
- Not peer-reviewed (n = 21)
- Not found (n = 21)
- Regarding healthcare providers (n = 13)
- Non-adult participants (n = 12)
- Inpatient setting (n = 6)
- Patients after transplant (n = 3)
- Focused on the family (n = 2)
- Patients in palliative care (n = 1)
- Not in English (n = 1)

Supplemental material placed on this supplemental material which has been supplied by the author(s) BMJ Publishing Group Limited (BMJ) disclaims all liability and responsibility arising from any reliance thereof.
### Supplementary Table 1. Characteristics of the included studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Country</th>
<th>Participants</th>
<th>Disease</th>
<th>Method</th>
<th>Self-management activity/recommendation</th>
<th>Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Audulv A (25)</td>
<td>2013</td>
<td>Sweden</td>
<td>21</td>
<td>Ischemic heart disease, rheumatic disease, chronic renal disease, inflammatory bowel disease, multiple sclerosis, diabetes</td>
<td>Qualitative</td>
<td>Exercise</td>
<td>To describe the different chronic illness self-management behavior patterns that individuals develop and maintain over time.</td>
</tr>
<tr>
<td>Bowling C. B (26)</td>
<td>2017</td>
<td>US</td>
<td>30</td>
<td>Chronic kidney disease</td>
<td>Qualitative</td>
<td>Diet and others</td>
<td>To understand the relationship among factors facilitating or impeding chronic kidney disease self-management in older adults.</td>
</tr>
<tr>
<td>Corcoran K. J (27)</td>
<td>2013</td>
<td>Australia</td>
<td>40</td>
<td>Chronic heart failure, diabetes, chronic</td>
<td>Qualitative</td>
<td>Managing symptoms</td>
<td>To identify the major disease-specific experiences of individuals living with diabetes, chronic heart failure, chronic obstructive pulmonary disease.</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Location</td>
<td>Study Size</td>
<td>Methodology</td>
<td>Health Conditions</td>
<td>Research Questions</td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>------</td>
<td>----------</td>
<td>------------</td>
<td>---------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Dixon A</td>
<td>2009</td>
<td>US</td>
<td>27</td>
<td>Qualitative</td>
<td>Obstructive pulmonary disease, High cholesterol, arthritis, cancer, diabetes, heart disease, depression, other</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>To explore how people with chronic conditions understand successful self-management, what barriers to self-management they face, and what strategies they employ to manage their condition and to cope with stress.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duguay C</td>
<td>2014</td>
<td>Canada</td>
<td>11</td>
<td>Qualitative</td>
<td>Hypertension, hyperlipidemia, diabetes, coronary artery disease, obesity, arthritis, chronic obstructive pulmonary disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>To describe the fundamental structure of adults’ experience with multimorbidity.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fuller B.G</td>
<td>2010</td>
<td>Australia</td>
<td>99</td>
<td>Qualitative</td>
<td>Older people with and without chronic heart or lung conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>To describe and understand factors which enhance and impede participation in physical activity for older adults with and without chronic illness.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Year</td>
<td>Country</td>
<td>Sample Size</td>
<td>Conditions</td>
<td>Methodology</td>
<td>Topic</td>
<td>Objective</td>
</tr>
<tr>
<td>---------------</td>
<td>------</td>
<td>---------</td>
<td>-------------</td>
<td>-----------------------------------</td>
<td>-------------</td>
<td>----------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Gardsten C</td>
<td>2018</td>
<td>Sweden</td>
<td>11</td>
<td>Diabetes</td>
<td>Qualitative</td>
<td>Recognizing and managing symptoms, exercise, diet</td>
<td>To identify perceived challenges related to self-management among recently diagnosed adults and those with longer experience of type 2 diabetes.</td>
</tr>
<tr>
<td>Gary R</td>
<td>2006</td>
<td>US</td>
<td>32</td>
<td>Diastolic heart failure</td>
<td>Qualitative</td>
<td>Diet</td>
<td>To describe the (a) performance of self-care behaviors and (b) demographic and clinical characteristics that affected self-care practices in women with diastolic heart failure.</td>
</tr>
<tr>
<td>Haverhal s L</td>
<td>2011</td>
<td>US</td>
<td>32 patients, 2 caregivers</td>
<td>Older people with one or more chronic medical conditions</td>
<td>Qualitative</td>
<td>Managing medication</td>
<td>To understand the medication self-management issues faced by older adults and caregivers that can be addressed by an electronic PHA (Personal health applications).</td>
</tr>
<tr>
<td>Janevic M.R</td>
<td>2013</td>
<td>US</td>
<td>25</td>
<td>Asthma plus others others</td>
<td>Mixed method</td>
<td>Recognizing and managing symptoms</td>
<td>To identify the self-management challenges faced by African American women with asthma and comorbidities, how they prioritize their conditions and behaviors perceived as beneficial across conditions.</td>
</tr>
<tr>
<td>Jerant A.F</td>
<td>2005</td>
<td>US</td>
<td>54</td>
<td>Diabetes, arthritis, depression, chronic heart</td>
<td>Qualitative</td>
<td>Managing symptoms, medication, diet</td>
<td>To elicit perceived barriers to active self-management and to</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Country</td>
<td>Sample size</td>
<td>Condition</td>
<td>Study Design</td>
<td>Theme</td>
<td>Research Question</td>
</tr>
<tr>
<td>-------</td>
<td>------</td>
<td>---------</td>
<td>-------------</td>
<td>-----------</td>
<td>--------------</td>
<td>-------</td>
<td>------------------</td>
</tr>
<tr>
<td>Majeed-Ariss R (36)</td>
<td>2015</td>
<td>UK</td>
<td>15</td>
<td>Diabetes</td>
<td>Qualitative</td>
<td>Diet and others</td>
<td>To explore the views of British-Pakistani women on how does having type 2 diabetes affects their identity and how does that relate to self-management.</td>
</tr>
<tr>
<td>Mickelson R (37)</td>
<td>2015</td>
<td>US</td>
<td>30</td>
<td>Heart failure</td>
<td>Mixed method</td>
<td>Managing medication</td>
<td>To examine how older adult patients with heart failure use cognitive artifacts for medication management.</td>
</tr>
<tr>
<td>Mphwanahe G (38)</td>
<td>2020</td>
<td>Malawi</td>
<td>39</td>
<td>Diabetes</td>
<td>Qualitative</td>
<td>Diet, exercise</td>
<td>To identify barriers, facilitators and support for diet and physical activity among adults with type 2 diabetes.</td>
</tr>
<tr>
<td>Munce S.E (39)</td>
<td>2014</td>
<td>Canada</td>
<td>26</td>
<td>Spinal cord injury</td>
<td>Qualitative</td>
<td></td>
<td>To understand the perceived facilitators and barriers to self-management to prevent secondary complications.</td>
</tr>
<tr>
<td>O’Connor R (40)</td>
<td>2016</td>
<td>US</td>
<td>31</td>
<td>Asthma</td>
<td>Qualitative</td>
<td>Managing symptoms</td>
<td>To understand their experience with assuming self-management roles for their asthma.</td>
</tr>
<tr>
<td>Paterson B (41)</td>
<td>2001</td>
<td>Canada</td>
<td>22</td>
<td>Diabetes</td>
<td>Qualitative</td>
<td></td>
<td>To investigate self-care decision making in diabetes.</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Year</td>
<td>Country</td>
<td>Age</td>
<td>Conditions</td>
<td>Study Design</td>
<td>Focus</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>------</td>
<td>---------</td>
<td>-----</td>
<td>------------</td>
<td>--------------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>Salim H</td>
<td>2021</td>
<td>Malaysia</td>
<td>26</td>
<td>Asthma</td>
<td>Qualitative</td>
<td>To explore how people with limited health literacy understand asthma and undertake self-management practices.</td>
<td></td>
</tr>
<tr>
<td>Steinman L</td>
<td>2020</td>
<td>US</td>
<td>70</td>
<td>Diabetes and hypertension</td>
<td>Qualitative</td>
<td>Exercise, managing symptoms</td>
<td>To understand the facilitators and barriers to chronic disease management and the acceptability, appropriateness, and feasibility of mHealth.</td>
</tr>
<tr>
<td>Van de Bovenkamp H</td>
<td>2017</td>
<td>Netherland</td>
<td>26</td>
<td>Rheumatic disease, diabetes, kidney failure, glaucoma, gout, kidney transplantation, heart failure, hearing disability, vision problems, cancer, tuberculosis, immune disease, high blood pressure,</td>
<td>Qualitative</td>
<td>Managing medication</td>
<td>To explore the way patient self-management is shaped in practice, including the implications of the difficulties encountered.</td>
</tr>
<tr>
<td>Name</td>
<td>Year</td>
<td>Country</td>
<td>Age</td>
<td>Comorbidities</td>
<td>Research Focus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>------</td>
<td>--------------</td>
<td>-----</td>
<td>-------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Williams A</td>
<td>2014</td>
<td>Australia</td>
<td>26</td>
<td>Diabetes, chronic kidney disease and cardiovascular disease</td>
<td>To examine the perceptions of a group of culturally and linguistically diverse participants with the comorbidities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zanini C</td>
<td>2018</td>
<td>Switzerland</td>
<td>20</td>
<td>Spinal cord injury</td>
<td>To identify styles of prevention that individuals with spinal cord injury adopt to deal with the risk of developing pressure injuries.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Supplementary Table 2. Extracts from the included studies and codes

<table>
<thead>
<tr>
<th>Author</th>
<th>Extract</th>
<th>Codes</th>
</tr>
</thead>
</table>
| Audulv et al. (25) | For other participants lifestyle changes were harder to maintain in their daily lives. For example, exercise could be difficult for participants with chronic or episodic pain and/or fatigue. Some participants with rheumatism described how they adapted their exercise, depending on current symptoms. For example, X alternated between walks, gym exercise, and swimming depending on her levels of pain: “If I have pain, then I notice that the only exercise I can do is swimming [...] I do not go out and take walks if I have a whole lot of pain in my feet” (rheumatism, 30 months after diagnosis). Other people with chronic pain struggled during the two and a half years to find an exercise they could perform despite their pain. For Y, exercise had been an important part of her life before she developed rheumatism but after her diagnosis it was difficult for her to maintain fitness: “Because I can’t move the way I used to]. I can’t go on speedy walks or bike or so. I don’t use the weighting machine, but can feel it [increased weight] on the clothes” (12 months after diagnosis). | 1. Not understanding symptoms and modify exercises accordingly, to maintain the same lifestyle as before.  
   a) some give up  
   b) some find and alternative |
| Bowling et al. (26) | Finally, Environmental Factors added layers of complexity to patients’ self-management activity (Figure 1, Environmental Factors box). In keeping with the ICF, these factors included the patient’s social and medical environment. Participants described wanting to fit into social structures (i.e., families) in which the majority of the group ate high sodium, high-protein foods and described real pressures of social acceptance. On the other hand, positive social support could aid the patient (“my wife sometimes will prepare different meals for me than she does for herself and my daughter”). When it came to the health care system, patients described deficient provider support (i.e., rushed physicians, little continuity). In addition, whereas patients are often concerned about these interacting factors and their “overall picture,” they described each provider as having a narrower focus on the relationship between the specific disease and the self-management recommendations of interest to their medical specialty (“I see four doctors here at the VA, so I can never remember who is doing, checking, for what”). | 1. Family acceptance. They want to fit in,  
   a) some people are supportive (e.g. wives)  
   2. Fragmented recommendations, difficult to keep up. Therefore, a challenge to integrate them.  
   a) no support and continuity of information form health professionals |
| Corcoran et al. (27) | Difficulty identifying exacerbations  
   Six participants reported difficulty with identifying exacerbations of CHF and making decisions about how or when to act. A woman in her 80s said: ‘I had a silly pain in the middle of my chest. I wasn’t gasping for my breath or anything like that, I just had the burps. I rang my daughter up. They got the ambulance to me and took me to hospital. They said I had a heart attack’ (APT027). | 1. Responsible to detect, understand and make a decision on accordingly to a symptom  
   a) a family member can provide help |
| Dixon et al. (28) | Some interviewees, including one at level 4, simply lacked self-belief that they could make the changes or were despondent as a result of a lack of success. One female interviewee felt that the changes that her provider was asking her to make were too radical and she did not feel capable to make the recommended changes at the pace required. Those with low levels of activation generally seemed to see themselves as the main reason why | 1. No confidence to implement recommendation.  
   a) does not agree. Not realistic |
they were not managing their condition well or doing the things that they were recommended to do by their doctor. The inability to take regular exercise was commonly blamed on being lazy, particularly by those with low activation. When interviewees expanded on the reasons in their responses they were able to identify practical constraints or barriers in the external environment, e.g. television, time constraints, and difficulty of scheduling exercise around work and domestic tasks or social engagements.

Duguay et al. (29) The physical limitations their health imposes — such as respiratory problems, joint pain, or lack of muscular endurance — affect their ability to perform many daily activities and even to hold a job. A father with obesity, chronic lower back pain, and osteoarthritis (among other diseases), which cause problems with mobility, mentioned that: “When it comes to my work, it’s really hard, I’m limited physically in what I do compared with what I was doing before, not easy at my age” (male, five chronic conditions).

Physical limitations also affect participants’ social lives, because they are constantly worrying about disease management (medication, treatment, restriction), even while participating in social activities, and could feel excluded. “My cousin has a cabin in the woods 2 hr away and doesn’t dare invite me anymore because of my health” (female, six chronic conditions). In general, participants in this sample preferred to do things alone rather than to deal with the pressure of spending time with others. Finally, some participants said that multimorbidity also affects their sex life, another dimension of social life: “I find it difficult not being able to do the same activities as before, both in terms of going out and having sex” (male, five chronic conditions). So, I endure the pain. [Drug A] and [Drug B] raise my sugar level. Let’s say I want to buy myself a treadmill to exercise so that I can improve my strength. I can’t do it; I’ll have too much pain in my knees. I’ll still have some pain everywhere” (male, five chronic conditions).

Fuller et al. (30) Skills and Knowledge

In both groups, there was general lack of understanding regarding the intensity and duration of physical activity required to confer health benefits. Many saw the intention to undertake regular activity as being sufficient, but there was limited knowledge and understanding of how to monitor physical activity levels and set appropriate targets. Whilst some Active Living participants had previously acquired a degree of motivation for physical activity from their attendance at pulmonary or CR programs, few were confident that they had the skills or knowledge needed to maintain ongoing regular physical activity.

Gardsten et al. (31) Health issues

Both groups, expressed uncertainty about how blood glucose levels are affected by exercise, eating habits and medication. Medical treatment and physical reactions contributed to a complex picture of how blood glucose levels should be balanced. For example, one challenge was to understand how blood glucose levels are managed enough to be able to perform other activities in daily life (work, social).

1. Physical limitations are not managed enough to be able to perform other activities in daily life (work, social).
2. Difficulty scheduling and fitting exercises around work, domestic tasks and social engagement.

a) not being invited in trips
b) accomplish activities alone to avoid social pressure.
affected during physically demanding work. Both groups also had to manage medication, and thus needed to understand the effects of the drugs on them individually and the different names used for identical drugs. It was also challenging to realize that diabetes is a chronic disease and to understand how blood glucose levels and daily routines affect each other.

Healthy living

Other challenges for both groups involved physical activity, such as how to balance physical activity in leisure with physical activity at work. One participant in the recently diagnosed group assumed that physical activity in terms of walking or climbing stairs at work only affected blood cholesterol values. The participant (Table 3, quote 3.2) was asked how he engaged in physical activity even though he often travelled to different construction sites. He assumed that physical activity needs to be exercised in another way for maximum health benefit. The experienced group had tried to learn to live healthily and, especially, to avoid complications based on the information they had received.

Healthy living

Both groups faced challenges in learning how to plan meals and develop regular and healthier eating habits (quote 4.2). Shopping for healthful products such as bread, yogurt, and beverages was also challenging, especially reading the small text of lists of ingredients and relating the content to their own health status. For those who lived alone, it was challenging having to cook and eat alone, since eating at restaurants contributed to higher costs of living. At work, both groups tried to minimize stress. Travel was also more challenging as they had to plan meals and balance sleep and stress while away from home. Both groups described challenges in finding suitable everyday routines for healthy living. The experienced group perceived challenges in translating general knowledge to their individual circumstances, such as balancing insulin therapy with their particular personal needs. To change their eating habits more easily, they wished that the diabetes nurse had taught them what they could or should eat, rather than what they ought to avoid.

Gary, R (32)

Married women and those with caretaking responsibilities described preparing what their family members preferred rather than food items on their recommended low-sodium diet. For example, one woman jokingly remarked, “if I fixed food like I am supposed to eat, no one would show up at the table and I don’t blame them using no seasoning.” Women were reluctant to give up culturally influenced dietary practices. For example, they commonly used pork for seasoning in vegetables such as greens and beans despite being aware that pork contained high sodium amounts. Eating at restaurants was considered a rare treat for many participants and a time when most women admitted they did not adhere to sodium restrictions. For example, one woman said, “Eating out is something special and I like eating my favorite things salt or no salt.”

1. Not part of family routine

2. Difficulty scheduling and fitting exercises around work, domestic tasks and social engagement. Difficulty with other self-management activities like planning meals (at home, at work, in travels).

a) not able to translate general knowledge and apply in individual circumstances
b) wished more practical information from health professionals
Haverhals et al. (33) | Several participants in the study visited practitioners of alternative forms of health care that included nutritionists, chiropractors, acupuncturists, or homeopaths. Many of these participants were frustrated about conflicting information that they received from their primary care doctor and alternative care providers regarding their health, the etiology of their illnesses, and the safety and effectiveness of their conventional and complementary medication regimens. In general, these participants did not feel that their allopathic doctors supported alternative care and therefore did not always tell them about alternative medications or therapies that they were pursuing. For 2 participants in particular, this was a source of confusion and stress regarding medication management and decision making: The biggest problem in my mind for my personal planning and decision making is the kind of conflict between my primary care doctor, traditional medicine man and this alternative [practitioner] — who happens to be a chiropractor — but he has done a big study of supplements. Consequently, I take 20 or 25 pills a day. My primary care physician just doesn’t care a hoot about all those supplements … Most people do not take all the pills I take, I’ve discovered. They take prescription pills, but I take magnesium and calcium and some brain pills and all kinds of stuff, and those are very important to the alternative medicine person in my life. But they are just uh … minimized totally by the primary care doctor so I feel like I’m fighting two sides. [Confirmatory focus group 2 participant]. Another participant asked: If you don’t follow the regimen, do you feel any different? Response: “Yes, I do…But then I don’t know which one to blame or credit!”

1. The challenge of making sense of conflicting information, decision-making about the right medication
   a) search alternative health care
   b) not feeling supported by their doctors

2. Difficulties in understanding which medication brought which effect.

Janevic et al. (34) | Pain and mobility limitations have direct and indirect effects on asthma and asthma management. Several women described pain or mobility limitations resulting from comorbid conditions as interfering with the physical tasks involved in asthma management, such as housecleaning, or even inhaler use, as described by one woman:

Another woman described not being able to discern if her symptoms were caused by her anxiety issues or because her asthma was “being really weird”. She thought at the time it was her asthma but later found out that her symptoms were due to her anxiety.

1. Physical limitations are not managed enough to be able to perform other physical tasks (e.g. housecleaning). Difficulty understanding the cause of her symptoms.

Jerant et al. (35) | Poor communication with physicians
Several participants reported feeling “rushed” through doctor visits: “The doctor doesn’t have time to be thorough,” and “I just can’t talk to my doctor because there isn’t time.” Several mentioned that, as a result, they had not been able to develop an adequate understanding of what caused their diseases, what their effects were, and how best to manage them. Many participants also had concerns about aspects of their physician’s communication style. Some were global (e.g. “My doctor doesn’t communicate well”), while others were more specific (“The doctor doesn’t listen to me” and “The doctor won’t consider any alternative options, just pushes pills”).

Other family-related issues concerned spousal support.

1. Not being attended properly in order to understand information and being able to apply it.
   a) health professionals rushed

2. Challenge to follow diet.
   a) some lack of support from family members
   b) some were helped by family members
Some participants mentioned spouses who would not cook appropriate foods or help support weight loss efforts, or who expected homes and families to be cared for in the same way as before the participants had developed their illnesses. Losing a job or having to quit work because of illnesses created problems at home for many participants, particularly men who found themselves suddenly at home all the time without much to do. While participants who perceived strong support at home seemed better able to cope with their conditions, some expressed distress related to depending on others. For example, one woman spoke of her 21-year-old grandson having to care for her and still go to school (“It’s so hard on him”). A few participants lived alone and had little or no support from family or friends but had found others to help meet their needs. For example, one elderly woman who lived alone had the delivery man put the wood for her stove on a bench on the porch because she could not bend over and lift it from the floor of the porch.

Pain

Pain kept many subjects from doing what they most wanted to do by making it hard for them to stand, walk and sit for long periods of time. As a result, some had dropped highly valued social engagements such as going to church or get together.

Supporting family is a barrier to self-management

An important role for participants was supporting their families in their roles as wife, mother and daughter-in-law. Women perceived putting the family’s needs before their own as a key barrier to self-management: Looking after him would affect my health. Sometimes I would be unwell in myself and I would be tired and would not want to do any work. But my husband was so poorly that I had to. He stayed in hospital a lot, going, coming back, visiting, doing everything with young children.

All participants considered the most important familial responsibility to be the care of young children. Mothers with young children talked about feeling rushed and having conflicting priorities. Older women recalled that management of their diabetes had been harder when their children were younger. Women with grown-up children talked about feeling generally supported by their offspring, although two women offered an alternative view. X and Y, the two participants with the most limited English, held views that suggested they sometimes felt unsupported by their families: Things looked blurry, lop-sided. I was in bed, and the pictures hanging on the wall, I couldn’t see them well. I told my daughter “I can’t see well”. Before they all used to think I was just saying it, just joking, but one day I was sitting and I said “Seriously I can’t see, take me somewhere” and they took me to the optician. The optician said “Yes, it’s leaking at the back”, now they are trying laser treatment but it’s not working.

First and second generation women frequently commented that men with diabetes sought and received more practical family support than they did, particularly from spouses. Two of participants’ husbands had T2D and
they spoke from that experience: My husband had diabetes after I got it. He got it later on you can say 10–12 years back.... So I have to control his diet and his things, “You should take care of your feet. You should go for a walk. You should eat this. You should eat not this one.” So my experience is that um men they don’t care for you but you have to care for them.

**Mickelson et al. (37)**

A striking observation was that many patients, caregivers, and clinicians had incomplete or incompatible knowledge regarding medication management. Patients do not always know what medications they were taking, their medications names, directions for use, or what effects to expect (Table 3a). Several patients lacked knowledge about the relationship between medications and symptoms, and, therefore, when it was appropriate to take medications.

We observed several instances of “misfit,” in which artifacts were incompatible with patients, other artifacts, routines, and environments of use. Instances of artifact-artifact misfit included differences between patients’ and clinicians’ artifacts. For example, patients’ scales or BP cuffs produced readings different from their clinics’. Patients’ homemade or modified medication lists often differed from those generated by the EHR. Artifact-person misfit occurred when cognitive artifacts were ill-suited for older users, their experiences, mental models, limitations, and daily routines.

There were also four major disadvantages. The first was related to integrating or reconciling multiple representations. Clinic visit communication was rarely structured around patient artifacts such as personal medication, lists and both clinicians and patients showed difficulty understanding each other’s lists. The multitude of lists and frequent updates was challenging, with some patients using outdated or incorrect lists. Once a pillbox was filled, it took effort to verify and identify the dispensed medications; patients described medication errors due to similar-looking medications or misfiling the pillbox.

**Mphwanthe et al. (38)**

During social events such as weddings and when travelling, participants expressed concern that they could not consume recommended foods. As such, they improvised or ate what was available at that moment and often reduced the amount consumed. Some participants also indicated that the food served during special events such as weddings and parties is considered delicious and difficult to resist. At parties, I do eat the foods that are there because the foods are usually delicious. On Christmas day, I neglected my condition and I ate delicious foods with my children, and my blood sugar is always high. Additionally, when travelling to different areas within the country, participants found it difficult to find appropriate food to purchase because most of the food sold along the way [street foods] are often not recommended for T2DM management.

Fear of public ridicule

Although involvement in physical activity is required for diabetes management, fear of the potential negative connotations from society acted as a setback to freely participate in different forms of activities. ‘I sometimes

| 1. Incomplete knowledge on what to expect from medications. What symptoms were affected by medications and how did they change? |
| 2. Recommendations and artifacts not customized to environment, age, daily routines |
| a) health professionals did not take these aspects in consideration |

| 1. Difficult to follow diet recommendations in another circumstances (e.g. travel, weddings). |
| 2. Challenge in performing exercise because of fear of public ridicule. |
| a) family not supportive |
| b) society stigma |
| Munce et al. (39) | Caregiver burnout  
Caregiver burnout was identified as a major barrier to self-management on the part of individuals with traumatic SCI and this was well-recognized across all participant groups. Given the role that family members/caregivers play in care processes and overall well-being of individuals with traumatic SCI, several participants believed that caregiver burnout could threaten the sustainability of these critical supports. Indeed, the dual role of family members—most often wives in the current study—as both a spouse and performing the duties of a nurse was highlighted as a stressor. A lack of specialized or targeted services/programs for family members/caregivers to address this burden was also noted. | 1. Caregiver burnout as a key obstacle to self-management, undermine the sustainability of crucial assistance. |
| O'Conor et al. (40) | Patients reported frequent lifestyle limitations as a result of their asthma such as a limited ability to do daily tasks or housework, inability to have pets or engage in formerly enjoyable social activities, such as dancing or sports, in an effort to avoid possible triggers. Lastly, they reported restricted freedom of movements due to their asthma, such as the inability to leave their home, especially during extreme weather. Some stated that they purposely avoided locations where they might encounter a trigger, while others stated that they needed to modify activities that required physical exertion.  
Self-monitoring was another patient-reported strategy. Facilitators of active self-monitoring included checking peak flow to assess symptoms and determine changes in asthma control. Additionally, patients reported staying within their known limits and not exerting themselves in a manner that would bring on asthma symptoms. One challenge to self-monitoring is the uncertainty about whether shortness of breath, fatigue, or cough was due to asthma or some other chronic illness. One patient also reported being unable to discern when her asthma symptoms are worsening and received no warning signs before an asthma attack, “I worry because it is silent, suddenly I feel suffocated. I worry because I don't feel symptoms to warn me.”  
The patient did not recognize that daily albuterol use was indicative of poor control. Consistent with this perception, a theme of marginalized expectations of health status was identified. Patients had accepted a level of shortness of breath or restricted freedom of movement as a result of asthma and did not recognize the potential quality of life he or she could achieve with greater asthma control. | 1. Physical limitations are not managed enough to be able to perform activities (e.g. housecleaning, having pets, social activities).  
a) chose to avoid them  
2. Self-monitoring is difficult. Unclear if shortness of breath, exhaustion, or cough (symptoms) are caused by asthma or another chronic condition.  
a) not being able to achieve self-management made them to depend on medication. |
| Paterson et al. (41) | Participants concurred that despite the compassionate and competent manner of many health professionals, their response to patients' experiential knowledge often betrayed their essential allegiance to professional dominance. Several indicated that attempts to assume an active role in decisions about their care were met at | 1. Lack of trust between patient and provider. The way of delivering information can affect their ability to make decisions. |
times with obvious skepticism and, at other times, with anger by health care professionals. For example, many participants told stories of episodes where health care professionals encouraged them to participate in decisions about their care, but then immediately discounted what the patient offered in terms of data.

Participants perceived such incidents as ‘not walking the talk’ of empowerment. They stated that until they know that they can be open with a health care professional about their ideas and experiences, they cannot engage in participatory decision making. Participants stated that practitioners most often communicate their distrust of experiential knowledge in their response to patients’ statements about what they believed or desired in their disease management. Three participants indicated that some practitioners respond to such statements by emphasizing the unpredictable nature of diabetes and the complexities of diabetes management that are beyond patients’ knowledge and abilities.

Inadequate resources for decision making

Participants identified a number of resources necessary for them to engage in participatory decision making with practitioners. This included information, time and monetary. Participants stated that the way information is given to persons with chronic illness could affect the willingness and ability to engage in decision making with the practitioner. For example, when practitioners spoke in medical jargon they could not understand, they perceived it as accentuating the power differential between the practitioner and themselves. ‘If he can't be bothered to talk so I can understand him, he doesn't really want me to make the decision with him’. Five participants stated that practitioners who do give information irrelevant to their unique situations impair the ability to use that information. A common example was when health care professionals suggested interventions to be used at home without considering the architectural, social or financial constraints that prohibit such a plan.

**Salim et al. (42)**

Stigmatizing experiences were challenging and inevitably influenced self-management decisions. Sports and physical activities such as playing football were identified as essential activities in embodying health identities, particularly among two young men in this study. Thus, for these participants, using an inhaler before a game or during a match demonstrated ‘weakness’ and invited unwanted social reactions.

**Steinman et al. (43)**

Although individuals and PEs knew about evidence-based chronic disease management strategies, there were deficits in IMB skills to carry out these strategies on a regular basis. 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. As one patient shared: For me, the most significant content is about physical exercise—how to do physical exercise properly and what are the advantages of doing physical exercise?
### Challenges to incorporating recommended dietary changes into their daily routine

- Households meals are prepared by other household members and other household members prefer more salt and sugar for better taste, they work long days and get fatigued when they do not eat their typical foods, and healthier foods are more expensive and harder to access.

#### Van de Bovenkamp et al. (44)

- For other patients, quality of life means that they are less active self-managers. They take their prescribed medication and speak up in medical consultations only when something is very important to them or when relatives push them to do so. However, generally, they do not play an active role in consultations, do not look for information about their condition or make adjustments to their medical regimen to fit their daily lives better. These patients value medical paternalism; they tend to follow doctors' orders and expect professionals to decide in their best interests. They feel that the professionals know better than them and to play a more active role would limit their quality of life.

#### Williams et al. (45)

- However, some participants had traditional roles caring for the family, which interfered with their self-care. A Greek participant stated: I have three (grown) men to look after and it influences my medicine taking. (Participant 36). Other participants cared for sick family members which was an added stress, and prioritized their care over their own at times. A participant stated: Carer for parents. Blood pressure up to 240 [mmHg] systolic- ‘stressful’- and father has tumor of the liver. I put out tablets for parents and myself. . . I give pills to Mum. Sometimes Mum forgets she has already had them so I keep them in my room. (Participant 11).

### Discussions

1. **Difficulties in fitting medical regime to daily life routines because they are passive in asking for knowledge and information, leave the decision to health professionals.**

1. **Prioritizing family need over self-care.**

1. **Different ideas of responsibility for self-management.**

   a) guidance of caregivers or health professionals

   b) found solutions themselves (problemsolvers)

---

### Supplementary Table 3. Themes and subthemes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Articles contributing to the themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environment support</td>
<td>Family and cultural norms</td>
<td>• Bowling et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Gary et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Jerant et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Majeed et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Mphwanthe et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Munce et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Williams et al.</td>
</tr>
<tr>
<td></td>
<td>Health professionals and guiding communication</td>
<td>• Bowling et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Dixon et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Haverhals et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Jerant et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Mickelson et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Paterson et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Van de Bovenkamp et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Zanini et al.</td>
</tr>
<tr>
<td></td>
<td>Society and chronic disease perceptions</td>
<td>• Duguay et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Mphwanthe et al.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Salim et al.</td>
</tr>
<tr>
<td>Comprehension gap</td>
<td>Reading the body</td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td>------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Audulv et al.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Corcoran et al.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Fuller et al.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Gardsten et al.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Haverhals et al.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Janevic et al.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• O'Conor et al.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Steinman et al.</td>
<td></td>
</tr>
</tbody>
</table>

| Applying information | • Dixon et al. |
|                     | • Gardsten et al. |
|                     | • Jerant et al.  |