Factors influencing the integration of self-management in daily life in chronic conditions: A scoping review of qualitative evidence.

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-066647
Article Type:	Original research
Date Submitted by the Author:	15-Jul-2022
Complete List of Authors:	Qama, Enxhi; Swiss Paraplegic Research, Rubinelli , Sara ; Swiss Paraplegic Research, Diviani, Nicola; Swiss Paraplegic Research
Keywords:	QUALITATIVE RESEARCH, General diabetes < DIABETES & ENDOCRINOLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Spine < ORTHOPAEDIC & TRAUMA SURGERY, SOCIAL MEDICINE, Heart failure < CARDIOLOGY

SCHOLARONE™
Manuscripts

Factors influencing the integration of self-management in daily life in chronic conditions: A scoping review of qualitative evidence.

Enxhi Qama[1,2*], Sara Rubinelli[1,2], & Nicola Diviani[1,2]

[1] Swiss Paraplegic Research, Nottwil, Switzerland

[2] Department of Health Sciences and Medicine, University of Lucerne, Lucerne, Switzerland

* Corresponding author at:
Swiss Paraplegic Research
Person-centered Healthcare & Health Communication Group
Guido A. Zäch Strasse 4
6207 Nottwil
Switzerland
+41 41 939 65 78
enxhi.qama@paraplegie.ch

sara.rubinelli@paraplegie.ch
nicola.diviani@paraplegie.ch

Keywords: social medicine; qualitative research; quality in healthcare; general diabetes, spine, heart failure

Word count: 3995

Abstract

Objective: Living an enjoyable life despite a chronic condition means being able to integrate disease self-management (SM) in daily life activities. For a successful SM integration, it is crucial for individuals to learn how to respond to unexpected situations by prioritizing and making informed decisions in their unique contexts. This scoping review aims to map the literature on chronic conditions and describe what influences the process of SM integration into a person's day-to-day roles and routines.

Methods: Arksey and O'Malley's methodology for conducting a scoping review guided the study, followed by a thematic narrative analysis of qualitative evidence.

Results: Twenty-three studies were included. The narrative analysis indicates that familial traditions, health professionals' guidance, and societal stigma might be factors that shape a patient's approach in adjusting and merging medical requirement with non-medical activities. Additionally, health communication aspects like complex and confusing medical information seem to challenge patients' ability to plan in advance how to better perform SM outside of their comfort zone.

Conclusions: The integration of SM requirements in a daily routine is a challenge faced by patients across different complex chronic conditions. Patients believe that health professionals do not share the same principles as them on what constitutes an effective way of solving problems in disease management. More training for both health professionals and patients in decision-making activities could promote a better collaboration and common understanding of patient's individual needs. The findings suggest that while there is still no clear conceptualization in the literature of the process of SM integration, factors that influence the way patients learn how to make their condition a natural part of life offers a good starting point. This study shows that more longitudinal qualitative research is required to capture

patients' learning needs through time, thereby, grasp the developmental character of the phenomenon.

Strengths and limitations of this study

- The methodology followed allowed for assessing an extensive body of literature, across different conditions and populations. This made possible to identify significant gaps in the literature, with longitudinal qualitative study design in SM being one of them.
- To our knowledge this is the first scoping review that explores these aspects, focusing only on qualitative evidence, and giving a significant contribution to the existing quantitative research.
- 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.

1. Introduction

In healthcare self-management (SM) has been defined as "learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition". (1, 2) Patients following SM practices have shown improvements in biological parameters and symptom management (3, 4) as well as in non-medical aspects, like a better lifestyle and management of daily roles in the society. (5-7)

Chronic conditions are often considered dynamic and constantly evolving; consequently, chronic condition SM is not always a straightforward experience. (8-10) As unexpected and new shifts in diseases occur, patients tend to abandon their acquired behaviors calling into question their sustainability over time. (11, 12) For instance, experiencing a new symptom or encountering information that contradicts previous knowledge puts patients in unknown territory to which the standard guidelines of SM might not apply. (13) Studies show that for people living with chronic conditions to maintain good health over time, rather than focusing solely on medical management, they must be able to integrate medical management in their daily roles and routines. (14-16)

In the context of chronic conditions, the concept of integration has been described as a developmental process where the identity and roles of the individual living with a chronic condition merge with that individual's environment and lifestyle, whereby a new unity is achieved that makes experiencing the condition a natural part of life. (17-20) Research has identified crucial prerequisite skills that facilitate the process of integration, such as problem-solving and decision-making. (21, 22) Indeed, problem-solving interventions have shown their impact on SM maintenance over time in conditions like diabetes, (23) depression, (24) or spinal cord injury. (25) Furthermore, studies have developed models explaining the trajectory of illness and SM integration in terms of its different phases and turning points, such as seeking effective management strategies or negotiating between different goals and objectives. (26, 27)

This important research has invaluable contribution to our understanding of how chronic conditions become an integral part of daily life. Decades of research have established the evidence on SM and the main reviews have highlighted aspects that influence SM behaviors, such as a person's emotional needs an health beliefs (28-30), knowledge and education, (31) access to healthcare, (32, 33) and communication with health professionals. (34)

Notwithstanding the valuable evidence, there is a need to comprehensively address the factors that may influence the trajectory of SM integration into a person's day-to-day roles and routines. Therefore, this article presents the results of a scoping review whose objective is to fill this gap in the literature by scoping the factors that challenge the integration of SM activities in daily life. The findings from this review can highlight possible research areas for further exploration in light of more efficient and sustainable SM of chronic conditions over time.

2. Methods

To reach the aforementioned objective we followed Arksey and O'Malley's methodology for conducting a scoping review. (35) This was deemed to be the most suitable methodology due to the aim of exploring comprehensively the factors influencing SM integration from the patient's perspective, rather than assessing the quality or strength of currently available evidence. (36) Once we formulated the research question, the next steps followed the guidelines of a scoping review: identification of relevant studies, selection, collection, summarization, and reporting of the results. For our review we adopted the PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist for reporting the steps (see Supplementary Material, PRISMA-ScR Checklist). (37)

2.1 Step 1: Identifying the research question

The review was guided by the following questions:

RQ1: What are the factors challenging the integration of SM behaviors in a chronic condition?

RQ2: How do these factors influence this process?

2.2 Search for relevant studies

In February 2022 we searched PubMed, Web of Science, Cinahl, and PsycInfo for relevant articles using a group of keywords 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. Considering the objective of this review, the literature search was influenced by two factors. First, situations reflecting the difficulties of merging disease-related routines that a person performs in their personal environment (at home, at work, and in public places) with everyday life situations and activities (family interactions, vacations, hobbies, and entertainment) were considered challenges of SM integration. Second, non-modifiable factors related to an individual's personal attributes, such as age, gender, or origins, were not objects of interest in the review.

Table 1. Search combination of keywords in databases

Database	Search 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.

2.3 Step 3: Selecting the studies

Our review included only articles that qualitatively describe challenges faced by patients in the SM of different chronic diseases and that reflect on the process of integration of disease-related routines. Qualitative research can offer a significant contribution to understanding the concept of SM integration as the participants themselves experience it. (38) Furthermore, qualitative interpretations can assist in the formulation of tailored recommendations in healthcare communication interventions given by practitioners or other interested actors. (39, 40)

We based the selection of studies on the following eligibility criteria: (1) qualitative studies, (2) written in English, (3) adult participants, (4) original and peer-reviewed, and (5) outpatient settings. Furthermore, only studies portraying health-related SM activities in the patient's personal environment, not in healthcare facilities (i.e., taking medication at home, performing breathing exercises, doing physical activities, taking care of symptoms), were deemed eligible. Therefore, we excluded studies discussing SM as part of the healthcare system, such as planning doctor's appointments or having access to the healthcare system, as opposed to more personal and individual aspects of it. Finally, we excluded studies portraying any chronic condition with specific requirements for SM related to brain function, such as substance abuse, central nervous system disease, or insomnia, or conditions considered life-threating even after frequent monitoring, such as HIV/AIDS or cancer. (41) For the purpose of managing the large number of articles, we used bibliographic manager database EndNote. In Figure 1, summarizes the PRISMA (Preferred Reporting Items for Systematic Reviews and & Meta-Analyses) process. (42)

2.4 Step 4: Charting the data

We used a standardized table to extract relevant information from eligible articles. For each article, table 2 included the primary author, year of publication, country, sample size, place of recruitment, type of disease, study design, and aim of the study. Supplementary Table 1 summarized the data from the articles' results sections.

Table 2. Characteristics of the included studies

Author	**Year**	**Country**	**Participants**	**Disease**	**Method**	**Aim**
Audulv, A	2013	Sweden	21	Different	Qualitative	To describe the different chronic illness self-management behavior patterns that individuals develop and maintain over time.
Bowling, C. B	2017	US	30	Chronic kidney disease	Qualitative	To understand the relationship among factors facilitating or impeding chronic kidney disease self-management in older adults.
Corcoran, K. J	2013	Australia	40	Different	Qualitative	To identify the major disease-specific experiences of individuals living with diabetes, chronic heart failure, chronic obstructive pulmonary disease.
Dickson V	2011	US	99	Heart failure	Qualitative	To explore how comorbidity influences heart failure self-care.
Dixon, A	2009	US	27	Different	Qualitative	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.
Duguay, C	2014	Canada	11	Different	Qualitative	To describe the fundamental structure of adults' experience with multimorbidity.
Fuller, B.G	2010	Australia	99	Different	Qualitative	To describe and understand factors which enhance and impede participation in physical activity for older adults with and without chronic illness.
Gardsten, C	2018	Sweden	11	Diabetes	Qualitative	To identify perceived challenges related to self-management among recently diagnosed adults and those with longer experience of type 2 diabetes.
Gary, R	2006	US	32	Diastolic heart failure	Qualitative	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.
Haverhals, L	2011	US	32 patients, 2 caregivers	Different	Qualitative	To understand the medication self-management issues faced by older adults and caregivers that can be addressed by an electronic PHA (Personal health applications).

Janevic, M.R	2013	US	25	Asthma plus others	Mixed method	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.
Jerant, A.F	2005	US	54	Different	Qualitative	To elicit perceived barriers to active self-management and to accessing self-management support resources.
Majeed-Ariss, R	2015	UK	15	Diabetes	Qualitative	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.
Mickelson, R	2015	US	30	Heart failure	Mixed method	To examine how older adult patients with heart failure use cognitive artifacts for medication management.
Mphwanthe, G	2020	Malawi	39	Diabetes	Qualitative	To identify barriers, facilitators and support for diet and physical activity among adults with type 2 diabetes.
Munce, S.E	2014	Canada	26	Spinal cord injury	Qualitative	To understand the perceived facilitators and barriers to self-management to prevent secondary complications
O'Conor R	2016	US	31	Asthma	Qualitative	To understand their experience with assuming self-management roles for their asthma.
Paterson, B	2001	Canada	22	Diabetes	Qualitative	To investigate self-care decision making in diabetes
Salim, H	2021	Malaysia	26	Asthma	Qualitative	To explore how people with limited health literacy understand asthma and undertake self-management practices.
Steinman, L	2020	US	70	Different	Qualitative	To understand the facilitators and barriers to chronic disease management and the acceptability, appropriateness, and feasibility of mHealth.
Van de Bovenkamp, H	2017	Netherland	26	Different	Qualitative	To explore the way patient self-management is shaped in practice, including the implications of the difficulties encountered.
Williams, A	2014	Australia	26	Different	Qualitative	To examine the perceptions of a group of culturally and linguistically diverse participants with the comorbidities.
Zanini, C	2018	Switzerland	20	Spinal cord injury	Qualitative	To identify styles of prevention that individuals with spinal cord injury adopt to deal with the risk of developing pressure injuries.

2.5 Step 5: Collating, summarizing and reporting the results

We extracted from the results section of the articles the information on challenging aspects, such as adjustments in recommendations, decision-making, problem-solving, and situations when SM recommendations interfere with other non-health-related daily life routines or activities.

We implemented a thematic narrative approach to analyze the collected data. This entailed, becoming familiar with the extracted results sections and their contexts and then grouping them into categories and themes according to the identified similarities. (43)

2.6 Patient and public involvement

None

3. Results

3.1 Study characteristics

After screening the abstracts of 9,360 articles, 717 were included for full-text screening. Of these, 694 studies were deemed ineligible. Ultimately, 23 articles in total were included for synthesis. The studies were conducted between 2000 and 2022. The majority (10) are from the United States; there are three from Australia, three from Canada, two from Sweden, and one each from Switzerland, the United Kingdom, Malawi, the Netherlands, and Malaysia. These 21 qualitative studies and two mixed-methods studies (from which only the qualitative data were extracted) represent more than 790 participants. Most of the articles focus on a mix of different chronic conditions (n = 11), diabetes (n = 4), cardiovascular diseases (n = 3), spinal cord injury (n = 2), asthma (n = 2), and kidney disease (n = 1). Twenty-two studies used a crossed-sectional design, and only one study followed a longitudinal approach for data collection and analysis. (44) Most of the studies aim at exploring facilitators and barriers of SM (n = 11). Eight studies describe disease experiences. Two studies explore decision-making and adaptation styles in SM. One study describes the different shapes of SM in daily practice and one investigates the patterns of SM behaviors over time.

3.2 Thematic narrative analysis

The synthesis of results yielded two main categories: the *supportive environment* and the *comprehension gap*. The supportive environment describes the practical and emotional help received from people who are present in their daily lives and is grouped into three themes: *family and cultural norms*, *health professionals and guiding communication*, and *society and chronic disease perceptions*. The comprehension gap describes how an individual creates their own understanding of biological information and its methodological implementation in practice and is grouped into two themes: *reading the body* and *applying information*.

3.2.1 Supportive environment

Participants in different studies define their environment as essential for developing long-lasting SM behaviors that are incorporated in other daily activities. The notion of a *supportive environment* includes a group of people contributing to an individual's SM by providing practical and emotional support, such as health professionals, family, and friends, or society in general.

3.2.1.1 Family and cultural norms

The review shows that cultural norms or gender roles within a family can influence the perceptions of personal responsibility in disease SM. Jerant et al. depict the perceived barriers to SM among individuals with different chronic conditions and show that good SM includes support and attention from one's spouse. For instance, a spouse who did not help with appropriate food preparation was considered to hinder a patient's efforts to lose weight. (45) Munce et al. interviewed patients with spinal cord injury 2–25 years after injury to understand their perceived facilitators and barriers to SM. Participants describe that caregivers go through a burnout phase, and this jeopardized the sustainability of their SM practices. (46) Majeed-Aris et al. describe how diabetes affects participants' identities as wives and mothers. Self-managing their diabetes while performing other roles at home seems like an impossible task. (47) Similarly, driven by traditional family caring responsibilities, participants in Williams et al.'s study find it challenging to integrate self-care routines with other activities, like caring for other sick family members. (48) Finally, female participants in Gary et al.'s describe their position of taking care of the home and preparing food for the family. According to one participant, if she cooks the food the way she is supposed to eat it (no seasoning), no one will show up at the dining table. (49)

3.2.1.2 Health professionals and guiding communication

Another influencing factor is the guidance from health professionals in terms of providing instructions on practical aspects of SM. On the one hand there are patients who need active support from health professionals, and on the other hand there are those who want to be fully independent. For example, Zanini et al. explore differences in spinal cord injury between patients who do and do not follow SM recommendations concerning pressure injuries. Participants whom the authors identify as "delegators," prefer a passive role in their SM, which requires constant advice from health professionals. (50) Similarly, participants in Van de Bovenkamp et al.'s study explain the importance of medical paternalism. As they find it difficult to take an active role in SM, they require health professionals to accommodate their informational needs and facilitate their decision-making. (51) Three other studies describe how broken communication channels with health professionals hindered patients' efforts to solve difficult SM situations. In their mixed-methods study on patients with heart failure, Mickelson et al. examine how participants use cognitive artifacts for medication management. Participants, despite being motivated and eager to participate in their disease management, sometimes struggle to reconcile their personal experience with the recommendations they receive from physicians. (52) Participants in Dickson et al.'s study experience the information coming from different providers as fragmented. Consequently, they struggle to integrate everything in a comprehensive way, which hinders their ability to develop an effective SM style. (53) Finally, Haverhals et al. identify a similar issue. Conflicting information impedes participants in developing problem-solving and decision-making skills because of low understanding of medication side effects, especially which medication produces which side effect. (54)

3.2.1.3 Society and chronic disease perceptions

A more general idea of support is associated with predefined societal perceptions of chronic conditions. Patients feel that they convey a certain image to people, making it difficult for them to perform activities without feeling judged. For example, Bowling et al. interviewed individuals with chronic kidney disease to understand the relationships between factors that facilitate or impede SM of the disease. According to participants, being able to incorporate recommendations into their daily life routines is challenged by societal acceptance of disease management activities in non-medical environments; therefore, very often, they abandon these recommendations. (55) Similarly, Mphwanthe et al. explain that participants often feel stigmatized when they try to perform SM activities in their natural environment. They give the example of the challenge of performing physical activities in front of their children or the fact that they hide from neighbors due to fear of being ridiculed. (56) Paterson et al. investigate the decision-making in SM for patients who have had diabetes for over 15 years. When discussing participatory decision-making, they mention that they often experience skepticism and distrust from health professionals regarding their experiential knowledge of the disease. They perceive this attitude as the opposite of support in shared decision-making. (57) Finally, Salim et al. present the perspective of patients with low health literacy on asthma SM. Participants who engage in sporting activities struggle to maintain their health identity.

For instance, using an inhaler during a football match is considered a weakness that attracts judgmental reactions. (58)

3.2.2 Comprehension gap

A second category is the chronic disease comprehension gap in terms of biological cues and making sense of medical information in a "how-to" approach. Concretely, studies mention that being unable to distinguish symptoms or understand how the body reacts to medications or performed recommendations.

3.2.2.1 Reading the body

Participants' describe difficulties in recognizing deviations from standard physiological norms, which in return challenges making predictions and planning other daily activities in advance. For instance, O'Conor et al. interviewed patients with asthma to understand their experience of SM. They emphasize the struggle of assuming an active role in SM owing to low understanding of body cues and symptoms. Therefore, the SM skills they developed were lacking a sound base that could help them integrate health-related activities in their daily lives. (59) Janevic et al. conducted interviews with African American women with asthma and comorbidities to discuss how they prioritize their conditions. The participants face the same barrier of not being able to distinguish the cause of their symptoms. (60) In the same line, Corcoran et al.'s participants explain that they lack knowledge of how to identify exacerbations of chronic heart failure (61) and, therefore, do not know how and when to react.

3.2.2.2 Applying information

Finally, participants describe the challenge in applying the information they receive in practical instructions according to their individual circumstances. Audulv et al.'s longitudinal qualitative study aims at describing SM behaviors that individuals with different chronic conditions develop over time. They highlight that their symptoms make it difficult for them to keep up with other activities they enjoy. In particular, understanding the right moment to perform a physical activity, depending on their level of pain, is a difficult challenge to manage. (44) Participants in Steinman et al.'s study explain the difficulties of integrating physical activity in a normal routine, since they do not know what the right frequency, duration, and intensity are. (62) Fuller et al. conducted focus group interviews with 99 patients to identify facilitators of and barriers to older adults' participation in physical activity. Similarly, they lack an understanding of the appropriate intensity and duration of physical activity, which makes it impossible to monitor and set targets for disease management. (63) Participants suffering from type 2 diabetes in Gardsten et al.'s study describe not perceiving physical actions in work environments, like climbing stairs, as types of physical activity that fulfill doctors' recommendations. (64)

4. Discussion and further research

4.1 Discussion

This review aimed to scope and narratively describe the factors challenging the integration of health-related SM practices in the daily life of people with a chronic conditions. The results show that deciding whether to adjust or abandon SM is influenced by relationships with family members and society. Additionally, our analysis suggests that patients, express a need for better training and information coordination that would support their ability to plan daily activities in advance without compromising their health requirements.

These results align with the evidence that being diagnosed with a lifelong condition has huge repercussions on an individual's view of themselves and their identity, which in turn, requires building new relationships with people around them. (10, 28, 65) A large body of evidence presents important outcomes in SM that are associated with emotional and practical support from family members. (28, 29, 31, 34, 66) Studies on priority setting and decision-making shows that the way a person wishes to portray themselves and be viewed by others would strongly influence their SM practices, such as choosing not to use certain assistive devices because of how it will reflect on their image. (67, 68) Whitehead et al. explain that the ongoing normalization and contextualization of the chronic condition among family members help promoting and supporting SM. (69) Even though sometimes, families readjust their lives to accommodate the needs of the member living with the condition, such as in cases where the family member is a child (70-73); other times, as shown in our review patients choose to give up on recommendations and prioritize the needs of their family. (74-76) From our results we see that despite the vast interest of research on the effects of personal relationships on SM, patients fail to consider them as a fundamental part of health management. They do not see decision-making and problem-solving as activities that need to be performed with the participation of family members or by factoring societal perceptions of disease management, therefore they often report giving up on SM. Targeting these relationships as interventional components in initial phases of understanding a chronic illness could better shape patients' inner negotiations on a daily basis.

Literature on health information shows that people living with a chronic condition use strategy like developing self-awareness of the ways the body responds to certain stimuli or situations through trial and error (77-79) as well as constantly clarifying the information they receive. (80-82) For instance, in Mickelson et al.'s study, patients describe techniques for making sense of knowledge in medication management, including asking questions, verifying existing plans, or questioning the validity of medication choices made by clinicians. (80) Indeed, if we consider empowerment intervention programs, many of them are based on experiential learning principles and involve group discussions, practical exercises, or self-reflection. (69, 83) However, our review highlights that patients often remain unsatisfied with the trainings they receive and are often left with the responsibility of putting together pieces of information from different providers which translates in building unsuitable decision-making patterns in their SM. (84) Indeed, self-care of a chronic disease, as described by Anderson, is characterized by the paradox of patient empowerment and medical dominance. (85) Doctors have the tendency to medicalize self-care practices, labeling patients as non-compliant, which as shown in our review results in broken patient-provider communication in SM. (85) Research on problem-solving interventions have explored the differences in disease SM perceptions among physicians and patients and emphasizes that physicians define non-compliance with recommendations and the validity of patients' problems on the basis of their own interpretation of what constitutes a problem to be solved via SM. Therefore, what the health professional considers an irrational way of solving a problem might be the only rational choice for the patient. (86) Health professionals involved in disease management should be more aware of information translation gaps they have with the patients. This awareness could bring better support in decision-making and problem-solving trainings that could promote more sustainable and integrated SM activities. For example, health professions should take their time in understanding what are the goals a patient has in adjusting to their new life with a chronic condition. Health professionals should also be more coordinated in the support they give to their patients during important phases of SM integration, such as seeking the most effective and sustainable SM strategy that best fits the patient's context. (27)

Our review brings forward very interesting issues for further exploration. First, the household environment and relationships with family and friends should be taken into consideration for making SM activities part of a personalized intervention. Further research should explore how do patients experience the adaptation of their family members to their chronic disease, in light of understanding decision-making and problem-solving styles. Second, research should explore whether the differences between health professionals' and patients' perspectives on what constitutes a "problem" in chronic condition SM could affect the successful integration of SM activities. For example, gathering qualitative evidence on health professionals' experience of their patients' SM integration could enrich the evidence on that topic. (40)

Third, the literature evinces that integration implies change over time and is, therefore, a "process". (19) To develop a better conceptualization of SM integration and its different stages, more evidence is required on learning needs throughout all these phases. (87) This review identified one longitudinal study exploring different patterns of chronic illness SM. (44) However, long-term engagement in researching the process of SM integration would greatly enhance our understanding of how time interacts with each individual at different stages of living with a chronic condition. (88) Finally, it has become increasingly evident, especially since the COVID-19 pandemic, (89-91) that the sources of information patients consult can further influence the way they apply information in individual SM circumstances. (92-94) Further research on the influence of information seeking habits of patients with chronic conditions, could contribute in better interpretation of skills developed in SM.

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 conditions and populations. This made possible to identify significant gaps in the literature, with longitudinal qualitative study design in SM being one of them. Second, to our knowledge this is the first scoping review that explores these aspects, focusing only on qualitative evidence, and giving a significant contribution to the existing quantitative studies. Third, the implications offered by our findings could contribute in initiating personalized guidelines in patient education, that would in return increase and emphasize a more efficient influence of health care professionals on the behavior of their patients.

Notwithstanding the above contributions, 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 (36); instead, the aim was to provide an overview that is as comprehensive as possible of aspects of SM experience in daily setting that have not previously been systematically synthesized. The second limitation is the potential exclusion of relevant studies. 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. The collected data suggest several areas for further exploration. Almost all reviewed articles represent research conducted in Western countries. Although some culturally related patterns were mentioned in the analysis, further exploration of this topic should be undertaken to determine particularities that can be found in different countries and cultures. (95) This research entailed synthesizing evidence on a broad range of chronic diseases, including diabetes, asthma, cardiovascular diseases, spinal cord injury, and multimorbidity. Although this evidence can offer a strong basis for making generalizations about different conditions, more in-depth research on individual conditions should be carried out.

5. Conclusion

The integration of SM requirements in a daily routine is a challenge faced by patients across different complex chronic conditions. Patients believe that health professionals do not share the same principles as them on what constitutes an effective way of solving problems in disease management. More training for both health professionals and patients in decision-making activities could promote a better collaboration and common understanding of patient's individual needs. The findings suggest that while there is still no clear conceptualization in the literature of the process of SM integration, factors that influence the way patients learn how to make their condition a natural part of life offers a good starting point. This study shows that more longitudinal qualitative research is required to capture patients' learning needs through time, thereby, grasp the developmental character of the phenomenon.

Contributors

All authors contributed to the conceptualization of the study. ND and SR secured funds for the study. EQ and ND designed the study. 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.

Funding statement

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

Competing Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Statement

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

Disclaimer

The funding source had no role in the study's conceptualization, decision to publish, or preparation of the manuscript.

Patient consent

Not required

Data sharing statement

No additional data are available.

Exclusive license statement

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in BMJ Open and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

References

1. Lorig K. Chronic disease self-management - A model for tertiary prevention. American Behavioral Scientist. 1996;39(6):676-83.

2. Lorig K. Self-management of chronic illness: a model for the future. Generations: Journal of the American Society on Aging. 1993;17(3):11-4.

3. Holman H, Lorig K. Patients as partners in managing chronic disease: partnership is a prerequisite for effective and efficient health care. British Medical Journal Publishing Group; 2000.

4. Ory MG, Ahn S, Jiang L, Lorig K, Ritter P, Laurent DD, et al. National study of chronic disease self-management: six-month outcome findings. Journal of aging and health. 2013;25(7):1258-74.

5. Fries JF, McShane D. Reducing need and demand for medical services in high-risk persons. A health education approach. Western Journal of Medicine. 1998;169(4):201.

6. Lorig KR, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter P, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization - A randomized trial. Medical care. 1999;37(1):5-14.

7. Lorig KR, Hurwicz M-L, Sobel D, Hobbs M, Ritter PL. A national dissemination of an evidence-based self-management program: A process evaluation study. Patient education and counseling. 2005;59(1):69-79.

8. Shaul MP. From early twinges to mastery: the process of adjustment in living with rheumatoid arthritis. Arthritis & Rheumatism: Official Journal of the American College of Rheumatology. 1995;8(4):290-7.

9. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. Journal of Nursing Scholarship. 2012;44(2):136-44.

10. Robinson CA. Managing life with a chronic condition: The story of normalization. Qualitative health research. 1993;3(1):6-28.

11. Kwasnicka D, Dombrowski SU, White M, Sniehotta F. Theoretical explanations for maintenance of behaviour change: a systematic review of behaviour theories. Health psychology review. 2016;10(3):277-96.

12. Sniehotta FF, Schwarzer R, Scholz U, Schüz B. Action planning and coping planning for long-term lifestyle change: theory and assessment. European Journal of Social Psychology. 2005;35(4):565-76.

13. Mackey LM, Doody C, Werner EL, Fullen B. Self-Management Skills in Chronic Disease Management: What Role Does Health Literacy Have? Medical Decision Making. 2016;36(6):741-59.

14. Ambrosio L, Senosiain García JM, Riverol Fernández M, Anaut Bravo S, Díaz De Cerio Ayesa S, Ursúa Sesma ME, et al. Living with chronic illness in adults: a concept analysis. Journal of Clinical Nursing (John Wiley & Sons, Inc). 2015;24(17-18):2357-67.

15. Whittemore R, Roy C. Adapting to diabetes mellitus: A theory synthesis. Nursing science quarterly. 2002;15(4):311-7.

16. Lorig KR, Holman HR. Self-management education: history, definition, outcomes, and mechanisms. Annals of behavioral medicine. 2003;26(1):1-7.

17. Hernandez CA. Integration: the experience of living with insulin dependent (Type 1) diabetes. Canadian Journal of Nursing Research Archive. 1996:37-56.

18. King G, Cathers T, Brown E, Specht JA, Willoughby C, Polgar JM, et al. Turning points and protective processes in the lives of people with chronic disabilities. Qualitative health research. 2003;13(2):184-206.

19. Westra BL, Rodgers BL. The concept of integration: A foundation for evaluating outcomes of nursing care. Journal of Professional Nursing. 1991;7(5):277-82.

20. Whittemore R. Analysis of integration in nursing science and practice. Journal of Nursing Scholarship. 2005;37(3):261-7.

21. Hill-Briggs F. Problem solving in diabetes self-management: A model of chronic illness self-management behavior. Annals of Behavioral Medicine. 2003;25(3):182-93.

22. D'Zurilla TJ, Nezu AM. Problem-solving therapy. Handbook of cognitive-behavioral therapies. 2010;3:197-225.

23. Fitzpatrick SL, Schumann KP, Hill-Briggs F. Problem solving interventions for diabetes self-management and control: a systematic review of the literature. Diabetes research and clinical practice. 2013;100(2):145-61.

24. Gellis ZD, Kenaley B. Problem-solving therapy for depression in adults: a systematic review. Research on Social Work Practice. 2008;18(2):117-31.

25. Elliott TR, Shewchuk RM, Richards JS. Caregiver social problem-solving abilities and family member adjustment to recent-onset physical disability. Rehabilitation Psychology. 1999;44(1):104-23.

26. Audulv Å, Asplund K, Norbergh K-G. The integration of chronic illness self-management. Qualitative health research. 2012;22(3):332-45.

27. Hörnsten Å, Jutterström L, Audulv Å, Lundman B. A model of integration of illness and self-management in type 2 diabetes. Journal of Nursing and Healthcare of Chronic Illness. 2011;3(1):41-51.

28. Russell S, Ogunbayo OJ, Newham JJ, Heslop-Marshall K, Netts P, Hanratty B, et al. Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals. NPJ primary care respiratory medicine. 2018;28(1):1-13.

29. 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(1):320.

30. Corbett T, Cummings A, Calman L, Farrington N, Fenerty V, Foster C, et al. Self-management in older people living with cancer and multi-morbidity: A systematic review and synthesis of qualitative studies. Psycho-oncology. 2020.

31. Koch G, Wakefield BJ, Wakefield DS. Barriers and Facilitators to Managing Multiple Chronic Conditions: A Systematic Literature Review. Western journal of nursing research. 2014;37(4):498-516.

32. Miles C, Arden-Close E, Thomas M, Bruton A, Yardley L, Hankins M, et al. Barriers and facilitators of effective self-management in asthma: systematic review and thematic synthesis of patient and healthcare professional views. NPJ primary care respiratory medicine. 2017;27(1):57.

33. Schulman-Green D, Jaser SS, Park C, Whittemore R. A metasynthesis of factors affecting self-management of chronic illness. Journal of advanced nursing. 2016;72(7):1469-89.

34. Liddy C, Blazkho V, Mill K. Challenges of self-management when living with multiple chronic conditions Systematic review of the qualitative literature. Canadian Family Physician. 2014;60(12):1123-33.

35. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International journal of social research methodology. 2005;8(1):19-32.

36. Lucas PJ, Baird J, Arai L, Law C, Roberts HM. Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. BMC medical research methodology. 2007;7(1):1-7.

37. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Annals of internal medicine. 2018;169(7):467-73.

38. Seers K. Qualitative systematic reviews: their importance for our understanding of research relevant to pain. British journal of pain. 2015;9(1):36-40.

39. Dixon-Woods M, Fitzpatrick R, Roberts K. Including qualitative research in systematic reviews: opportunities and problems. Journal of evaluation in clinical practice. 2001;7(2):125-33.

40. Diviani N, Rubinelli S. Self-management of complex chronic conditions: Recommendations for qualitative health communication research. Qualitative Health Communication. 2022;1(1):122-33.

41. Sharfstein S, Chrvala CA. Definition of serious and complex medical conditions. 1999.

42. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. International Journal of Surgery. 2021;88:105906.

43. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.

44. Audulv Å. The over time development of chronic illness self-management patterns: a longitudinal qualitative study. BMC public health. 2013;13:452.

45. Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. Patient education and counseling. 2005;57(3):300-7.

46. Munce SE, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. BMC neurology. 2014;14:48.

47. Majeed-Ariss R, Jackson C, Knapp P, Cheater FM. British-Pakistani women's perspectives of diabetes self-management: the role of identity. Journal of clinical nursing. 2015;24(17-18):2571-80.

48. Williams A, Manias E, Cross W, Crawford K. Motivational interviewing to explore culturally and linguistically diverse people's comorbidity medication self-efficacy. Journal of clinical nursing. 2015;24(9-10):1269-79.

49. Gary R. Self-care practices in women with diastolic heart failure. Heart & Lung. 2006;35(1):9-19.

50. Zanini C, Brach M, Lustenberger N, Scheel-Sailer A, Koch HG, Stucki G, 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. Journal of Spinal Cord Medicine. 2020;43(2):247-56.

51. Bovenkamp HM, Dwarswaard J. The complexity of shaping self-management in daily practice. Health Expectations. 2017;20(5):952-60.

52. Mickelson RS, Willis M, Holden RJ. Medication-related cognitive artifacts used by older adults with heart failure. Health Policy and Technology. 2015;4(4):387-98.

53. Dickson VV, Buck H, Riegel B. A qualitative meta-analysis of heart failure self-care practices among individuals with multiple comorbid conditions. Journal of cardiac failure. 2011;17(5):413-9.

54. Haverhals LM, Lee CA, Siek KA, Darr CA, Linnebur SA, Ruscin JM, et al. Older adults with multi-morbidity: medication management processes and design implications for personal health applications. Journal of medical Internet research. 2011;13(2):e44.

55. Bowling CB, Vandenberg AE, Phillips LS, McClellan WM, Johnson TM, 2nd, Echt KV. Older Patients' Perspectives on Managing Complexity in CKD Self-Management. Clinical journal of the American Society of Nephrology : CJASN. 2017;12(4):635-43.

56. Mphwanthe G, Carolan M, Earnesty D, Weatherspoon L. Perceived barriers and facilitators to diet and physical activity among adults diagnosed with type 2 diabetes in Malawi. Global Public Health.

57. Paterson B. Myth of empowerment in chronic illness. Journal of advanced nursing. 2001;34(5):574-81.

58. Salim H, Young I, Lee PY, Shariff-Ghazali S, Pinnock H. 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. 2021.

59. O'Conor R, Martynenko M, Gagnon M, Hauser D, Young E, Lurio J, et al. A qualitative investigation of the impact of asthma and self-management strategies among older

adults. The Journal of asthma : official journal of the Association for the Care of Asthma. 2017;54(1):39-45.

60. Janevic MR, Ellis KR, Sanders GM, Nelson BW, Clark NM. Self-management of multiple chronic conditions among African American women with asthma: a qualitative study. Journal of Asthma. 2014;51(3):243-52.

61. 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. Australian health review : a publication of the Australian Hospital Association. 2013;37(1):19-25.

62. Steinman L, Heang H, van Pelt M, Ide N, Cui H, Rao 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 and uHealth. 2020;8(4):e13536.

63. Fuller BG, Stewart Williams JA, Byles JE. Active living--the perception of older people with chronic conditions. Chronic illness. 2010;6(4):294-305.

64. Gardsten C, Blomqvist K, Rask M, Larsson Å, Lindberg A, Olsson G. Challenges in everyday life among recently diagnosed and more experienced adults with type 2 diabetes: A multistage focus group study. Journal of clinical nursing. 2018;27(19-20):3666-78.

65. Charmaz K. The body, identity, and self: Adapting to impairment. Sociological quarterly. 1995;36(4):657-80.

66. Crespo C, Santos S, Canavarro MC, Kielpikowski M, Pryor J, Féres-Carneiro T. Family routines and rituals in the context of chronic conditions: A review. International Journal of Psychology. 2013;48(5):729-46.

67. Liu X-L, Willis K, Fulbrook P, Wu C-J, Shi Y, Johnson M. Factors influencing self-management priority setting and decision-making among Chinese patients with acute

coronary syndrome and type 2 diabetes mellitus. European Journal of Cardiovascular Nursing. 2019;18(8):700-10.

68. Bratzke LC, Muehrer RJ, Kehl KA, Kyoung Suk L, Ward EC, Kwekkeboom KL. Self-management priority setting and decision-making in adults with multimorbidity: A narrative review of literature. International journal of nursing studies. 2015;52(3):744-55.

69. Whitehead L, Jacob E, Towell A, Abu-Qamar M, Cole-Heath A. The role of the family in supporting the self-management of chronic conditions: A qualitative systematic review. Journal of clinical nursing. 2018;27(1-2):22-30.

70. Knafl KA, Deatrick JA. The challenge of normalization for families of children with chronic conditions. Pediatric nursing. 2002;28(1):49.

71. Hayes VE. Families and children's chronic conditions: Knowledge development and methodological considerations. Research and theory for nursing practice. 1997;11(4):259.

72. Santos S, Crespo C, Canavarro MC, Kazak AE. Family Rituals and Quality of Life in Children With Cancer and Their Parents: The Role of Family Cohesion and Hope. Journal of pediatric psychology. 2015;40(7):664-71.

73. Knafl K, Breitmayer B, Gallo A, Zoeller L. Family response to childhood chronic illness: Description of management styles. Journal of pediatric nursing. 1996;11(5):315-26.

74. Satink T, Josephsson S, Zajec J, Cup EH, de Swart BJ, Nijhuis-van der Sanden MW. Negotiating role management through everyday activities: narratives in action of two stroke survivors and their spouses. Disability and rehabilitation. 2016;38(24):2354-64.

75. Gallant MP, Spitze GD, Prohaska TR. Help or Hindrance? How Family and Friends Influence Chronic Illness Self-Management among Older Adults. Research on aging. 2007;29(5):375-409.

76. Martinez-Marcos M, De la Cuesta-Benjumea C. How women caregivers deal with their own long-term illness: a qualitative study. Journal of advanced nursing. 2014;70(8):1825-36.

77. Deshaies K, Hernandez CA. Integration: a phenomenon to explore in chronic nonmalignant pain (CNP). Pain Management Nursing. 2011;12(1):2-14.

78. Whittemore R, Chase SK, Mandle CL, Roy C. Lifestyle change in type 2 diabetes a process model. Nursing research. 2002;51(1):18-25.

79. Diviani N, Obrenovic J, Montoya CL, Karcz K. Disentangling health information appraisal competence: Results from an interdisciplinary scoping review and online consultation among Swiss stakeholders. PloS one. 2020;15(7):e0235474.

80. Mickelson RS, Unertl KM, Holden RJ. Medication Management: The Macrocognitive Workflow of Older Adults With Heart Failure. JMIR human factors. 2016;3(2):e27.

81. Dickson VV, Buck H, Riegel B. Multiple comorbid conditions challenge heart failure self-care by decreasing self-efficacy. Nursing research. 2013;62(1):2-9.

82. Vest JR, Gamm LD. Health information exchange: persistent challenges and new strategies. Journal of the American Medical Informatics Association. 2010;17(3):288-94.

83. Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: Polysemy or cacophony? Patient education and counseling. 2007;66(1):13-20.

84. Allen D, Badro V, Denyer-Willis L, Ellen Macdonald M, Paré A, Hutchinson T, et al. Fragmented care and whole-person illness: Decision-making for people with chronic end-stage kidney disease. Chronic illness. 2014;11(1):44-55.

85. Anderson RM. Patient empowerment and the traditional medical model: a case of irreconcilable differences? Diabetes care. 1995;18(3):412-5.

86. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. Jama. 2002;288(19):2469-75.

87. Hermanowicz JC. The longitudinal qualitative interview. Qualitative sociology. 2013;36(2):189-208.

88. Saldaña J. Longitudinal qualitative research: Analyzing change through time: Rowman Altamira; 2003.

89. Orso D, Federici N, Copetti R, Vetrugno L, Bove T. Infodemic and the spread of fake news in the COVID-19-era. European Journal of Emergency Medicine. 2020.

90. Rubinelli S, Ort A, Zanini C, Fiordelli M, Diviani N. Strengthening Critical Health Literacy for Health Information Appraisal: An Approach from Argumentation Theory. International journal of environmental research and public health. 2021;18(13):6764.

91. Zarocostas J. How to fight an infodemic. The Lancet. 2020;395(10225):676.

92. Diviani N, van den Putte B, Giani S, van Weert JC. Low health literacy and evaluation of online health information: a systematic review of the literature. Journal of medical Internet research. 2015;17(5):e4018.

93. Diviani N, Van den Putte B, Meppelink CS, van Weert JC. Exploring the role of health literacy in the evaluation of online health information: Insights from a mixed-methods study. Patient education and counseling. 2016;99(6):1017-25.

94. Zimmerman MS, Shaw Jr G. Health information seeking behaviour: a concept analysis. Health Information & Libraries Journal. 2020;37(3):173-91.

95. Paterson BL, Russell C, Thorne S. Critical analysis of everyday self-care decision making in chronic illness. Journal of Advanced Nursing (Wiley-Blackwell). 2001;35(3):335-41.

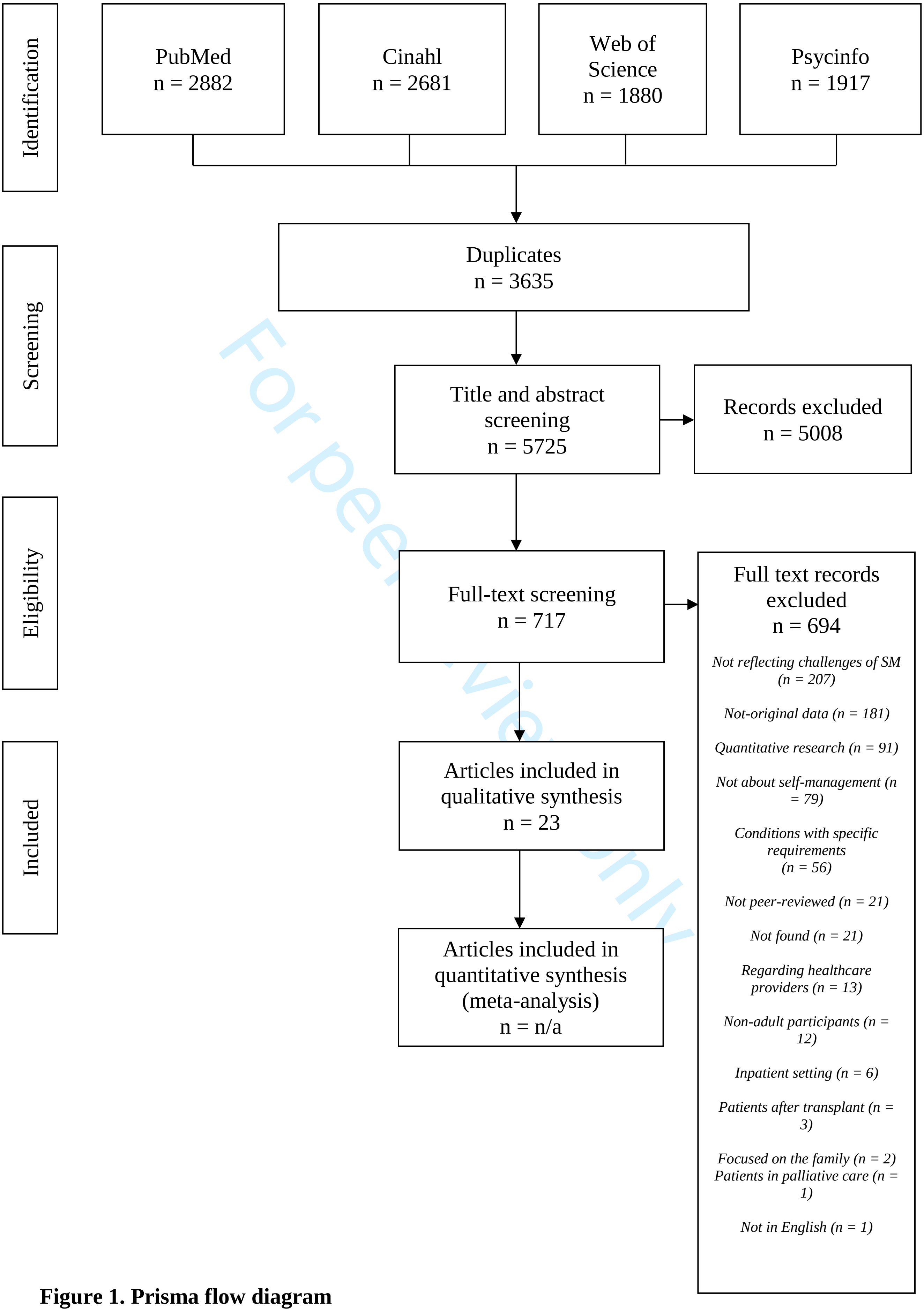


Figure 1. Prisma flow diagram

Supplementary Table 1. Result sections of the included studies

Author	Passage
Audulv, A	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).
Bowling, C. B	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”).
Corcoran, K.J	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).
Dickson V	Many struggled with integrating multiple self-care instructions, especially when HF self-care was perceived as conflicting with the other condition. Subjects reported receiving disease-specific instructions from providers (‘‘at the diabetic doctor’s office, they told me to lose weight. didn’t mention salt.’’) rather than an integrated plan of self-care. Fragmented self-care instructions seemed to

	force subjects to select one set of self-care behaviors to engage in. As a result, individuals failed to develop the skill necessary to practice adequate HF self-care. Individuals felt ill-prepared to carry out self-care and lacked skill in doing HF self-care within the context of another condition. Diet was an area of particular difficulty. One 58-year-old Caucasian male with HF, hyperlipidemia, and diabetes described his frustration, ''they say this [salt] will kill you. That will kill you. Just going into the supermarket is hard. am I supposed to live on bloody rice.''. Few in our sample who had a history of prior myocardial infarction, were proficient at recognizing the subtle symptoms of HF. However, they were attentive to warning signs like angina (''that pain here [pointing to chest] ...I don't mess around with that.''). The patient is then forced to make decisions (is it my sugar? is it my kidneys? is it my heart?) for which they are ill-equipped. This process ends in inadequate self-care skill and an increased risk of poor outcomes.
Dixon, A	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 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, C	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). Difficulties with access to the healthcare system Poor access to the healthcare system contributes to complicating the management of multimorbidity. Many health problems require medical follow-up, as well as occasional emergency visits. Participants find that making an appointment with their family physician or with medical specialists is difficult: "That's what's most complicated, what's hardest: Just making an appointment with my doctor" (female, nine chronic conditions). Obstacles include overloaded telephone lines at medical clinics and the inability to schedule an appointment less than several months in advance. One participant commented: "It's not the disease that I'm fighting; it's the healthcare system" (male, six chronic conditions).
Fuller, B.G	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, C	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 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. A challenge unique to the experienced group was extra costs of healthcare visits. They also found it difficult to engage in physical activity when physically restricted by a complication of diabetes, to access a gym or a pool in their vicinity, and to find an activity that fit their financial situation.
Gary, R	Dietary choices were influenced by numerous factors, including lack of money. For example, several participants were unable to purchase protein-rich foods and relied heavily on carbohydrates such as rice, beans, and bread for their diet. Other women cited a preference for vegetables because meat had become more difficult to chew as they got older. Widowed or single women prepared fewer meals. 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.”
Haverhals, L	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!”
Janevic, M.R	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.
Jerant, A.F	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''). Many participants were frustrated with delays in receiving test results. Difficulty getting appointments with specialist physicians was often perceived as being due to a primary care physician's unwillingness to place a referral. Difficulties communicating with nurses and other health professionals were seldom mentioned. Other family-related issues concerned spousal support. 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 met 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.
Majeed-Aris, R	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, R	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. Fourth, data were sometimes lost when, as described earlier, they were not recorded or communicated between patients and clinicians.
Mphwanthe, G	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 [once in a while] dance in my bedroom as part of exercise, because my children and other family members including the neighbors laugh at me when I dance as exercise

	outside the house' Indeed, neighbors disappoint us. One day a neighbor said, 'Why do you do all the household chores as if you don't have children? But for me this is part of my exercise'.
Munce, S.E	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.
O'Conor R	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.
Paterson, B	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 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, H	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, L	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 included that household meals are prepared by other household members and that 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, H	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, A	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).
Zanini, C	What distinguished the Delegators from the Thoughtfuls and the Selectives was their preference for passive (e.g. air-flow bed) versus active preventive measures (e.g. skin inspection), their tendency to act under the guidance of caregivers and not on personal initiative, and their preference for handing over responsibility prevention to others (e.g. homecare service) Additionally, the Delegators had high expectations from the performance of assistive devices (e.g. no need to change position in bed) and could consequently be annoyed if a PI developed despite their use. Selectives reported contacting experts for timely support and had a network of HPs that they could turn to for advice or care if they believed it necessary. Expertise in SCI seemed to be crucial especially for the Selectives, as some participants stated that they preferred to find solutions on their own rather than turning to HPs who had no expertise (e.g. general practitioners) In line with their preference for delegating the responsibility of prevention, the Delegators seemed to prefer more supervision (e.g. regular checkups in the outpatient clinic, home visits from the specialized counseling service).

ICF – International Classification of Functioning, Disability, and Health, CHF – chronic heart failure, HF – heart failure, CR – cardiac rehabilitation, T2D – type two diabetes, SCI – spinal cord injury, PI – pressure injury

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

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	
ABSTRACT			
Structured summary	2	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.	
INTRODUCTION			
Rationale	3	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.	
Objectives	4	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.	
METHODS			
Protocol and registration	5	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.	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	
Information sources*	7	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.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	
Data charting process‡	10	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.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	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).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	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.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	
DISCUSSION			
Summary of evidence	19	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.	
Limitations	20	Discuss the limitations of the scoping review process.	
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	
FUNDING			
Funding	22	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.	

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 by Arksey and O'Malley (6) and Levac 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).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

BMJ Open

Factors influencing the integration of self-management in daily life routines in chronic conditions: A scoping review of qualitative evidence.

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-066647.R1
Article Type:	Original research
Date Submitted by the Author:	16-Nov-2022
Complete List of Authors:	Qama, Enxhi; Swiss Paraplegic Research, Rubinelli , Sara ; Swiss Paraplegic Research, Diviani, Nicola; Swiss Paraplegic Research
Primary Subject Heading:	Communication
Secondary Subject Heading:	Qualitative research, Rehabilitation medicine
Keywords:	QUALITATIVE RESEARCH, General diabetes < DIABETES & ENDOCRINOLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, SOCIAL MEDICINE, Heart failure < CARDIOLOGY

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]

[1] Swiss Paraplegic Research, Nottwil, Switzerland

[2] Department of Health Sciences and Medicine, University of Lucerne, Lucerne, Switzerland

* Corresponding author at:
Swiss Paraplegic Research
Person-centered Healthcare & Health Communication Group
Guido A. Zäch Strasse 4
6207 Nottwil
Switzerland
+41 41 939 65 78
enxhi.qama@paraplegie.ch

sara.rubinelli@paraplegie.ch
nicola.diviani@paraplegie.ch

Keywords: social medicine; qualitative research; quality in healthcare; general diabetes, heart failure

Word count: 3574

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 behaviors 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: PubMed, Web of Science, Cinahl, and PsycInfo

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 was synthesized and analyzed thematically. PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist was used for reporting the steps.

Results: Twenty-two studies were included. The thematic analysis brought up two overreaching 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.

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 made 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.

1. 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 behaviors 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 changes (11) is considered to facilitate self-management. (13) They suggest that patients need scheduling and prioritization skills in their familial and societal roles, such as work or special occasions like holidays and vacations. (11, 13). To better conceptualize 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 synthesize 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) says 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 summarizing 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.

2. Methods

To reach the aforementioned objective we followed Arksey and O'Malley's methodology for conducting a scoping review. (18) We adopted the PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist for reporting the steps (see Supplementary Material, PRISMA-ScR Checklist). (19)

2.1 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 familial and societal roles in people living with chronic conditions?

RQ2: How do these factors influence this process?

2.2 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 function (20) 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 characterized by a great amount of unpredictability and considered life-threating (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)."

2.3 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.

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.

2.4 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 (i.e.*' 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 Supplementary Figure 1. Prisma Flow chart).

2.5 Charting the data

Two reviewers prepared a standardized table to extract relevant information from eligible articles. Data extraction was conducted independently by the same reviewers. Table 2 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. Supplementary Table 1 summarized 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 with author's chosen quotes for illustration.

Table 2. Characteristics of the included studies

Author	**Year**	**Country**	**Participants**	**Disease**	**Method**	**Self-management activity/recommendation**	**Aim**
Audulv A (25)	2013	Sweden	21	Ischemic heart disease, rheumatic disease, chronic renal disease, inflammatory bowel disease, multiple sclerosis, diabetes	Qualitative	Exercise	To describe the different chronic illness self-management behavior patterns that individuals develop and maintain over time.
Bowling C. B (26)	2017	US	30	Chronic kidney disease	Qualitative	Diet and others	To understand the relationship among factors facilitating or impeding chronic kidney disease self-management in older adults.
Corcoran K. J (27)	2013	Australia	40	Chronic heart failure, diabetes, chronic obstructive pulmonary disease	Qualitative	Managing symptoms	To identify the major disease-specific experiences of individuals living with diabetes, chronic heart failure, chronic obstructive pulmonary disease.
Dixon A (28)	2009	US	27	High cholesterol, arthritis, back pain or sciatica, cancer, diabetes,	Qualitative	Exercise and other	To explore how people with chronic conditions understand successful self-management, what barriers to self-management they face, and what strategies

				heart disease, depression, other			they employ to manage their condition and to cope with stress.
Duguay C (29)	2014	Canada	11	Hypertension, hyperlipidemia, diabetes, coronary artery disease, obesity, arthritis, chronic obstructive pulmonary disorder	Qualitative	Managing symptoms, managing medications	To describe the fundamental structure of adults' experience with multimorbidity.
Fuller B.G (30)	2010	Australia	99	Older people with and without chronic heart or lung conditions	Qualitative	Exercise, managing symptoms	To describe and understand factors which enhance and impede participation in physical activity for older adults with and without chronic illness.
Gardsten C (31)	2018	Sweden	11	Diabetes	Qualitative	Recognizing and managing symptoms, exercise, diet	To identify perceived challenges related to self-management among recently diagnosed adults and those with longer experience of type 2 diabetes.
Gary R (32)	2006	US	32	Diastolic heart failure	Qualitative	Diet	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.
Haverhals L (33)	2011	US	32 patients, 2 caregivers	Older people with one or more chronic medical conditions	Qualitative	Managing medication	To understand the medication self-management issues faced by older adults and caregivers that can be addressed by an electronic

							PHA (Personal health applications).
Janevic M.R (34)	2013	US	25	Asthma plus others	Mixed method	Recognizing and managing symptoms	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.
Jerant A.F (35)	2005	US	54	Diabetes, arthritis, depression, chronic heart failure, asthma, other	Qualitative	Managing symptoms, medication, diet	To elicit perceived barriers to active self-management and to accessing self-management support resources.
Majeed-Ariss R (36)	2015	UK	15	Diabetes	Qualitative	Diet and others	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.
Mickelson R (37)	2015	US	30	Heart failure	Mixed method	Managing medication	To examine how older adult patients with heart failure use cognitive artifacts for medication management.
Mphwanthe G (38)	2020	Malawi	39	Diabetes	Qualitative	Diet, exercise	To identify barriers, facilitators and support for diet and physical activity among adults with type 2 diabetes.
Munce S.E (39)	2014	Canada	26	Spinal cord injury	Qualitative		To understand the perceived facilitators and barriers to self-management to prevent secondary complications.

O'Conor R (40)	2016	US	31	Asthma	Qualitative	Managing symptoms	To understand their experience with assuming self-management roles for their asthma.
Paterson B (41)	2001	Canada	22	Diabetes	Qualitative		To investigate self-care decision making in diabetes.
Salim H (42)	2021	Malaysia	26	Asthma	Qualitative	Managing symptoms	To explore how people with limited health literacy understand asthma and undertake self-management practices.
Steinman L (43)	2020	US	70	Diabetes and hypertension	Qualitative	Exercise, managing symptoms	To understand the facilitators and barriers to chronic disease management and the acceptability, appropriateness, and feasibility of mHealth.
Van de Bovenkamp H (44)	2017	Netherland	26	Rheumatic disease, diabetes, kidney failure, glaucoma, gout, kidney transplantation, heart failure, hearing disability, vision problems, cancer, tuberculosis, immune disease, high blood pressure,	Qualitative	Managing medication	To explore the way patient self-management is shaped in practice, including the implications of the difficulties encountered.

				high cholesterol, gastric bypass surgery			
Williams A (45)	2014	Australia	26	Diabetes, chronic kidney disease and cardiovascular disease	Qualitative	Managing medication	To examine the perceptions of a group of culturally and linguistically diverse participants with the comorbidities.
Zanini C (46)	2018	Switzerland	20	Spinal cord injury	Qualitative	Managing complications	To identify styles of prevention that individuals with spinal cord injury adopt to deal with the risk of developing pressure injuries.

2.6 Collating, summarizing 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. (47) 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 Supplementary Table 2. 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?

2.7 Patient and public involvement

None

3. Results

3.1 Study characteristics

After screening the abstracts of 9,360 articles, 717 were included for full-text screening. Of these, 694 studies were deemed ineligible. Ultimately, 22 articles in total were included for synthesis (25-46), as illustrated in Supplementary Figure 1. The studies were conducted between 2001(41) and 2021 (42). The majority (n = 9) are from the United States (26, 28, 32-35, 37, 40, 43); there are three from Australia (27, 30, 45), three from Canada (29, 39, 41), two from Sweden (25, 31), and one each from Switzerland (46), the United Kingdom (36), Malawi (38), the Netherlands (44), and Malaysia (42). There are twenty qualitative studies

(25-33, 35, 36, 38-46) and two mixed-methods studies (34, 37) (from which only the qualitative data were extracted) represent more than 690 participants. Articles cover a wide range of conditions including diabetes (n = 12) (25, 27-29, 31, 35, 36, 38, 41, 43-45), cardiovascular conditions (n = 11) (25, 27-30, 32, 35, 37, 43-45), lung conditions (n = 7) (27, 29, 30, 34, 35, 40, 42), rheumatic diseases (n = 5) (25, 28, 29, 35, 44), kidney disease (n = 4) (25, 26, 44, 45), spinal cord injury (n = 2) (39, 46), cancer (n = 2) (28, 44), depression (n = 2) (28, 35), inflammatory bowel disease (n = 1) (25), multiple sclerosis (n =1) (25), back pain or sciatica (n = 1) (28), obesity (n = 1) (29), glaucoma (n = 1) (44), hearing disability (n = 1) (44), vision problems (n = 1) (44), tuberculosis (n = 1) (44), immune disease (n = 1) (44) and gastric bypass surgery (n = 1) (44). Twenty-one studies used a crossed-sectional design (26-46), and only one study followed a longitudinal approach for data collection and analysis. (25) Most of the studies aim at describing the experience, understanding and performance of self-management (n = 9). (27, 29, 32, 36-38, 40, 42) Six studies aim at exploring facilitators and barriers of self-management (n = 6). (26, 28, 30, 35, 39, 43) Fours studies explore issues and challenges in self-management. (31, 33, 34, 44) Two studies explore decision-making and adaptation styles in self-management (41, 46) and one investigates the patterns of self-management behaviors over time (25).

3.2 Thematic analysis

The synthesis of results yielded two main overreaching 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*.

3.2.1 Environment support

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

3.2.1.1 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. (26, 32, 35, 36, 38, 39, 45) While some of them highlight that they receive unconditional support (26, 35), others emphasize that sometimes gender roles (e.g. spouses and mothers) within a family could jeopardize self-care (35, 36, 45). They feel the pressure of having to choose and prioritize between their self-management routines or family needs (26, 32, 38, 45) : "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 prioritized their care over their own at times". (45)

3.2.1.2 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. (26, 28, 33, 35, 37, 41, 44, 46) Some patients advocated for medical paternalism and needed an active support for every problem and decisional process in their self-management. (44, 46) More independent patients reported receiving fragmented information in a hurried encounter with their physicians (26, 33): "participants reported feeling ‘‘rushed’’ through doctor visits: 'The doctor doesn’t have time to be thorough,". They also believed that advice was not based on the reality of the patient's environment (28, 37, 41): "cognitive artifacts were ill-suited for older users, their experiences, mental models, limitations, and daily routines". As a result, they felt ill-equipped to deal with unanticipated situations and make educated decisions on how to deal with them (35, 41): "practitioners who give information irrelevant to their unique situations impair the ability to use that information". Finally, this led to a loss of faith in the health professionals, which caused patients to experience feelings of incompetence and disempowerment. (28, 41)

3.2.1.3 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 until they were confident enough to follow instructions in various settings (29, 38, 42): "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". (42) Stigmatizing events like distancing attitudes (29) or unpleasant reactions from friends or peers (42), inevitably influenced self-management and brought out feelings of isolation (29, 38): "'My cousin has a cabin in the woods 2 hours away and doesn't dare invite me anymore because of my health'. In general, participants in this sample preferred to do things alone rather than to deal with the pressure of spending time with others". (29)

3.2.2 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.

3.2.2.1 Reading the body

This theme describes the difficulties that patients experience in recognizing deviations from standard physiological norms and how it challenges their ability plan self-management in different situations. (25, 27, 30, 31, 33, 34, 40, 43) This can often make it difficult for them to apply self-management recommendations in the best way possible in order to reach the desired result (30, 31, 33, 43): "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". (43) 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. (31, 33, 34, 40) A typical example was: one challenge was to understand…. how blood glucose levels and daily routines affect each other." (31) Sometimes family members could provide help in identifying and reacting to certain cues (27); in more independent cases these knowledge gaps could make patients clueless of the fact that a good life can be achieved with proper self-management: "Patients had accepted a level of 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". (40)

3.2.2.2 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. (28, 31, 35) Patients faced difficulties in exercising planning and scheduling skills to fit self-management activities around work or social engagements. (28, 31) Additionally, there were patients that tended to give up their recommendations because of poor information evaluating skills like in this example: "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". (31)

4. Discussion and further research

4.1 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 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) depression, (49) or spinal cord injury. (50) More studies should explore methods used by health professionals to build personalized 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 conditions (51-54) 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 conceptualization 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 error (59-61) 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. (25) 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)

4.2 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 conceptualization of the search strategy. We may have neglected some aspects of the routines of self-management, since there is no clear conceptualization 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 synthesizing evidence on a broad range of chronic diseases and self-management activities. Although it can offer a strong basis for generalization, more in-depth research on individual conditions or self-management activities and recommendations should be carried out.

5. 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 personalized interventions for patient education in chronic condition self-management.

Contributors

All authors contributed to the conceptualization 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.

Funding statement

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

Competing Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Statement

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

Disclaimer

The funding source had no role in the study's conceptualization, decision to publish, or preparation of the manuscript.

Patient consent

Not required

Data sharing statement

All data relevant to the study are included in the article or uploaded as supplementary information.

Exclusive license statement

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive

licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in BMJ Open and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

For peer review only

References

1. Richard AA, Shea K. Delineation of Self-Care and Associated Concepts. Journal of Nursing Scholarship. 2011;43(3):255-64.

2. Van de Velde D, De Zutter F, Satink T, Costa U, Janquart S, Senn D, et al. Delineating the concept of self-management in chronic conditions: a concept analysis. BMJ open. 2019;9(7):e027775.

3. Goodman RA, Posner SF, Huang ES, Parekh AK, Koh HK. Peer reviewed: defining and measuring chronic conditions: imperatives for research, policy, program, and practice. Preventing chronic disease. 2013;10.

4. O'Halloran J, Miller GC, Britt H. Defining chronic conditions for primary care with ICPC-2. Family practice. 2004;21(4):381-6.

5. Shaul MP. From early twinges to mastery: the process of adjustment in living with rheumatoid arthritis. Arthritis & Rheumatism: Official Journal of the American College of Rheumatology. 1995;8(4):290-7.

6. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. Journal of Nursing Scholarship. 2012;44(2):136-44.

7. Robinson CA. Managing life with a chronic condition: The story of normalization. Qualitative health research. 1993;3(1):6-28.

8. Kwasnicka D, Dombrowski SU, White M, Sniehotta F. Theoretical explanations for maintenance of behaviour change: a systematic review of behaviour theories. Health psychology review. 2016;10(3):277-96.

9. Sniehotta FF, Schwarzer R, Scholz U, Schüz B. Action planning and coping planning for long-term lifestyle change: theory and assessment. European Journal of Social Psychology. 2005;35(4):565-76.

10. Mackey LM, Doody C, Werner EL, Fullen B. Self-Management Skills in Chronic Disease Management: What Role Does Health Literacy Have? Medical Decision Making. 2016;36(6):741-59.

11. Koch G, Wakefield BJ, Wakefield DS. Barriers and Facilitators to Managing Multiple Chronic Conditions: A Systematic Literature Review. Western journal of nursing research. 2014;37(4):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. Canadian Family Physician. 2014;60(12):1123-33.

13. Schulman-Green D, Jaser SS, Park C, Whittemore R. A metasynthesis of factors affecting self-management of chronic illness. Journal of advanced nursing. 2016;72(7):1469-89.

14. Russell S, Ogunbayo OJ, Newham JJ, Heslop-Marshall K, Netts P, Hanratty B, et al. Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals. NPJ primary care respiratory medicine. 2018;28(1):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(1):320.

16. Miles C, Arden-Close E, Thomas M, Bruton A, Yardley L, Hankins M, et al. Barriers and facilitators of effective self-management in asthma: systematic review and thematic synthesis of patient and healthcare professional views. NPJ primary care respiratory medicine. 2017;27(1):57.

17. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. International journal of evidence-based healthcare. 2015;13(3):141-6.

18. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International journal of social research methodology. 2005;8(1):19-32.

19. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Annals of internal medicine. 2018;169(7):467-73.

20. Botvin GJ, Griffin KW, Scheier LM. Developmental trajectories of self-management skills and adolescent substance use. Salud y drogas. 2009;9(1):15-37.

21. Trivedi MH, Lin E, Katon WJ. Consensus recommendations for improving adherence, self-management, and outcomes in patients with depression. CNS spectrums. 2007;12(8 Suppl 13):1-27.

22. Chattopadhyay S, Karlsson J, Mañas A, Kanzaki R, Fredlund E, Murphy AJ, et al. Evolutionary unpredictability in cancer model system. bioRxiv. 2022:2022.06.01.494285.

23. Mansky PJ, Wallerstedt DB. Complementary medicine in palliative care and cancer symptom management. The Cancer Journal. 2006;12(5):425-31.

24. Harding R. Palliative care as an essential component of the HIV care continuum. The lancet HIV. 2018;5(9):e524-e30.

25. Audulv Å. The over time development of chronic illness self-management patterns: a longitudinal qualitative study. BMC public health. 2013;13:452.

26. Bowling CB, Vandenberg AE, Phillips LS, McClellan WM, Johnson TM, 2nd, Echt KV. Older Patients' Perspectives on Managing Complexity in CKD Self-Management. Clinical journal of the American Society of Nephrology : CJASN. 2017;12(4):635-43.

27. 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. Australian Health Review. 2013;37(1):19-25.

28. Dixon A, Hibbard J, Tusler M. How do People with Different Levels of Activation Self-Manage their Chronic Conditions? The patient. 2009;2(4):257-68.

29. Duguay C, Gallagher F, Fortin M. The experience of adults with multimorbidity: a qualitative study. Journal of comorbidity. 2014;4:11-21.

30. Fuller BG, Stewart Williams JA, Byles JE. Active living—the perception of older people with chronic conditions. Chronic illness. 2010;6(4):294-305.

31. Gardsten C, Blomqvist K, Rask M, Larsson Å, Lindberg A, Olsson G. Challenges in everyday life among recently diagnosed and more experienced adults with type 2 diabetes: A multistage focus group study. Journal of clinical nursing. 2018;27(19-20):3666-78.

32. Gary R. Self-care practices in women with diastolic heart failure. Heart & Lung. 2006;35(1):9-19.

33. Haverhals LM, Lee CA, Siek KA, Darr CA, Linnebur SA, Ruscin JM, et al. Older adults with multi-morbidity: medication management processes and design implications for personal health applications. Journal of medical Internet research. 2011;13(2):e44.

34. Janevic MR, Ellis KR, Sanders GM, Nelson BW, Clark NM. Self-management of multiple chronic conditions among African American women with asthma: a qualitative study. Journal of Asthma. 2014;51(3):243-52.

35. Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. Patient education and counseling. 2005;57(3):300-7.

36. Majeed-Ariss R, Jackson C, Knapp P, Cheater FM. British-Pakistani women's perspectives of diabetes self-management: the role of identity. Journal of clinical nursing. 2015;24(17-18):2571-80.

37. Mickelson RS, Willis M, Holden RJ. Medication-related cognitive artifacts used by older adults with heart failure. Health Policy and Technology. 2015;4(4):387-98.

38. Mphwanthe G, Carolan M, Earnesty D, Weatherspoon L. Perceived barriers and facilitators to diet and physical activity among adults diagnosed with type 2 diabetes in Malawi. Global Public Health.

39. Munce SE, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. BMC neurology. 2014;14:48.

40. O'Conor R, Martynenko M, Gagnon M, Hauser D, Young E, Lurio J, et al. A qualitative investigation of the impact of asthma and self-management strategies among older adults. The Journal of asthma : official journal of the Association for the Care of Asthma. 2017;54(1):39-45.

41. Paterson B. Myth of empowerment in chronic illness. Journal of advanced nursing. 2001;34(5):574-81.

42. Salim H, Young I, Lee PY, Shariff-Ghazali S, Pinnock H. 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. 2021.

43. Steinman L, Heang H, van Pelt M, Ide N, Cui H, Rao 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 and uHealth. 2020;8(4):e13536.

44. Bovenkamp HM, Dwarswaard J. The complexity of shaping self-management in daily practice. Health Expectations. 2017;20(5):952-60.

45. Williams A, Manias E, Cross W, Crawford K. Motivational interviewing to explore culturally and linguistically diverse people's comorbidity medication self-efficacy. Journal of clinical nursing. 2015;24(9-10):1269-79.

46. Zanini C, Brach M, Lustenberger N, Scheel-Sailer A, Koch HG, Stucki G, 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. Journal of Spinal Cord Medicine. 2020;43(2):247-56.

47. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.

48. Fitzpatrick SL, Schumann KP, Hill-Briggs F. Problem solving interventions for diabetes self-management and control: a systematic review of the literature. Diabetes research and clinical practice. 2013;100(2):145-61.

49. Gellis ZD, Kenaley B. Problem-solving therapy for depression in adults: a systematic review. Research on Social Work Practice. 2008;18(2):117-31.

50. Elliott TR, Shewchuk RM, Richards JS. Caregiver social problem-solving abilities and family member adjustment to recent-onset physical disability. Rehabilitation Psychology. 1999;44(1):104-23.

51. Crespo C, Santos S, Canavarro MC, Kielpikowski M, Pryor J, Féres-Carneiro T. Family routines and rituals in the context of chronic conditions: A review. International Journal of Psychology. 2013;48(5):729-46.

52. Gallant MP, Spitze GD, Prohaska TR. Help or Hindrance? How Family and Friends Influence Chronic Illness Self-Management among Older Adults. Research on aging. 2007;29(5):375-409.

53. Satink T, Josephsson S, Zajec J, Cup EH, de Swart BJ, Nijhuis-van der Sanden MW. Negotiating role management through everyday activities: narratives in action of two stroke survivors and their spouses. Disability and rehabilitation. 2016;38(24):2354-64.

54. Whitehead L, Jacob E, Towell A, Abu-Qamar M, Cole-Heath A. The role of the family in supporting the self-management of chronic conditions: A qualitative systematic review. Journal of clinical nursing. 2018;27(1-2):22-30.

55. Anderson RM. Patient empowerment and the traditional medical model: a case of irreconcilable differences? Diabetes care. 1995;18(3):412-5.

56. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. Jama. 2002;288(19):2469-75.

57. Audulv Å, Asplund K, Norbergh K-G. The integration of chronic illness self-management. Qualitative health research. 2012;22(3):332-45.

58. Hörnsten Å, Jutterström L, Audulv Å, Lundman B. A model of integration of illness and self-management in type 2 diabetes. Journal of Nursing and Healthcare of Chronic Illness. 2011;3(1):41-51.

59. Deshaies K, Hernandez CA. Integration: a phenomenon to explore in chronic nonmalignant pain (CNP). Pain Management Nursing. 2011;12(1):2-14.

60. Whittemore R, Chase SK, Mandle CL, Roy C. Lifestyle change in type 2 diabetes a process model. Nursing research. 2002;51(1):18-25.

61. Diviani N, Obrenovic J, Montoya CL, Karcz K. Disentangling health information appraisal competence: Results from an interdisciplinary scoping review and online consultation among Swiss stakeholders. PloS one. 2020;15(7):e0235474.

62. Mickelson RS, Unertl KM, Holden RJ. Medication Management: The Macrocognitive Workflow of Older Adults With Heart Failure. JMIR human factors. 2016;3(2):e27.

63. Dickson VV, Buck H, Riegel B. Multiple comorbid conditions challenge heart failure self-care by decreasing self-efficacy. Nursing research. 2013;62(1):2-9.

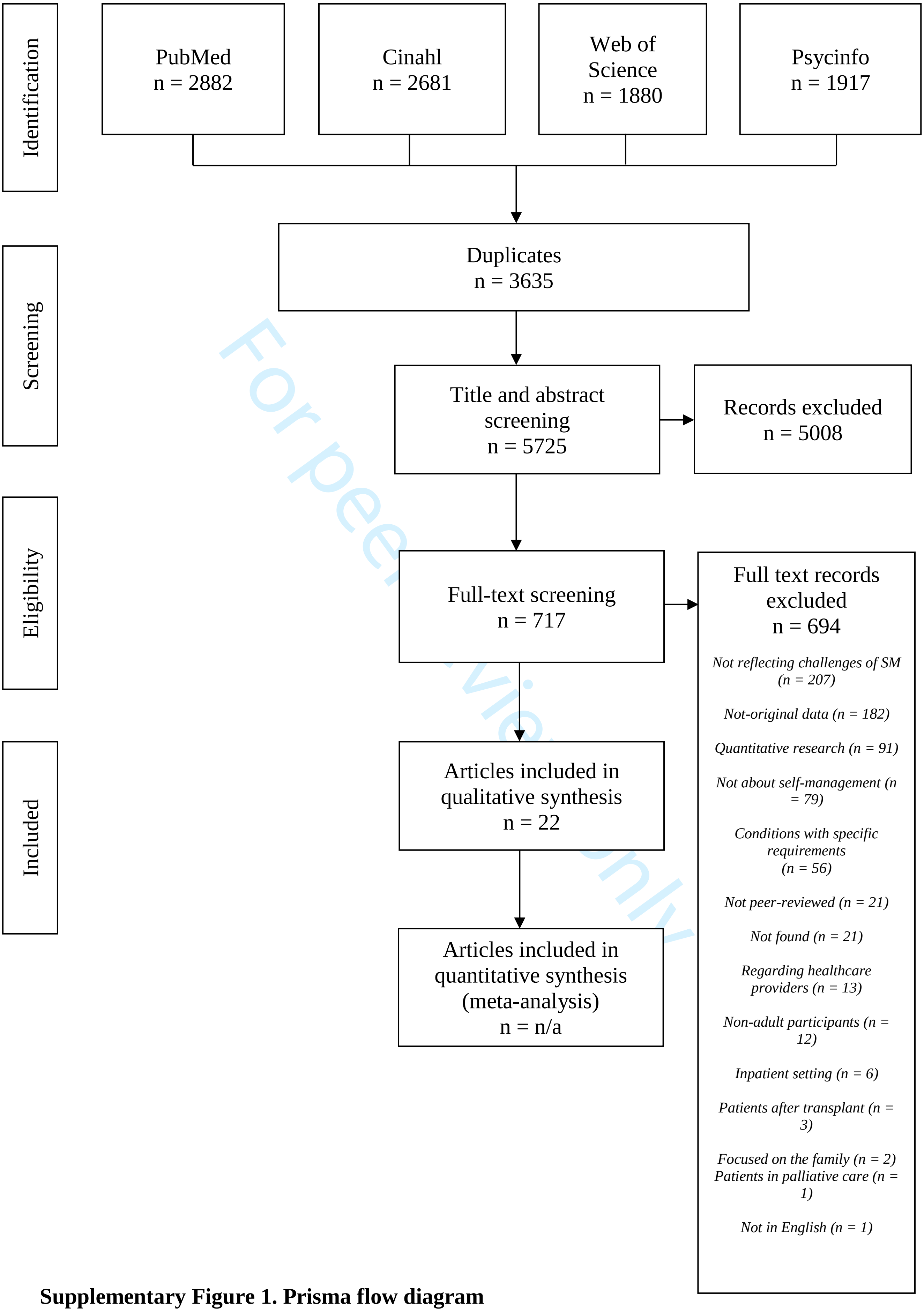
64. Vest JR, Gamm LD. Health information exchange: persistent challenges and new strategies. Journal of the American Medical Informatics Association. 2010;17(3):288-94.

65. Hermanowicz JC. The longitudinal qualitative interview. Qualitative sociology. 2013;36(2):189-208.

66. Saldaña J. Longitudinal qualitative research: Analyzing change through time: Rowman Altamira; 2003.

67. Lucas PJ, Baird J, Arai L, Law C, Roberts HM. Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. BMC medical research methodology. 2007;7(1):1-7.

68. Paterson BL, Russell C, Thorne S. Critical analysis of everyday self-care decision making in chronic illness. Journal of Advanced Nursing (Wiley-Blackwell). 2001;35(3):335-41.



Supplementary Figure 1. Prisma flow diagram

Supplementary Table 1. Extracts from the included studies and codes

Author	Extract	Codes
Audulv et al. (1)	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. (2)	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. (3)	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. (4)	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.	2. Difficulty scheduling and fitting exercises around work, domestic tasks and social engagement.
Duguay et al. (5)	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).	1. Physical limitations are not managed enough to be able to perform other activities in daily life (work, social). a) not being invited in trips b) accomplish activities alone to avoid social pressure.
Fuller et al. (6)	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.	1. Not understood the intensity and duration of the physical activity. No skills how to measure activity levels
Gardsten et al. (7)	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	1. Difficult to understand, read the symptoms. Also, how do daily routines influence symptoms?

	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.	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 an apply in in individual circumstances b) wished more practical information from health professionals
Gary, R(8)	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

Haverhals et al. (9)	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. (10)	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. (11)	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 met 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.	3. Physical limitations are not managed enough to be able to attend social engagements
Majeed-Aris et al. (12)	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	1. Wives, mothers, and daughters-in-law prioritize family needs first even though it affects their health. a) sometimes the husband is also sick b) sometimes the family is not supportive c) sometimes children are young and need care

	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. (13)	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.	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
Mphwanthe et al. (14)	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. Difficult to follow diet recommendations in another circumstances (e.g. travel, weddings). a) ate something else b) modified the portions c) ate the available food, prioritized family 2. Challenge in performing exercise because of fear of public ridicule. a) family not supportive b) society stigma

	[once in a while] dance in my bedroom as part of exercise, because my children and other family members including the neighbors laugh at me when I dance as exercise outside the house' Indeed, neighbors disappoint us. One day a neighbor said, 'Why do you do all the household chores as if you don't have children? But for me this is part of my exercise'.	
Munce et al.(15)	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. (16)	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. (17)	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.	a) jargon b) not relevant to their unique environment and situation
Salim et al. (18)	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.	1. Stigmatizing events were difficult and impacted self-management.
Steinman et al. (19)	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?	1. Knowledge gaps included frequency, intensity, and duration of physical activity and dietary modifications. Lacked the skills to incorporate the recommendation to daily routines .

	Challenges to incorporating recommended dietary changes into their daily routine included that household meals are prepared by other household members and that 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. (20)	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.	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 .
Williams et al.(21)	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).	1. Prioritizing family need over self-care.
Zanini et al. (22)	What distinguished the Delegators from the Thoughtfuls and the Selectives was their preference for passive (e.g. air-flow bed) versus active preventive measures (e.g. skin inspection), their tendency to act under the guidance of caregivers and not on personal initiative, and their preference for handing over responsibility prevention to others (e.g. homecare service) Additionally, the Delegators had high expectations from the performance of assistive devices (e.g. no need to change position in bed) and could consequently be annoyed if a PI developed despite their use. Selectives reported contacting experts for timely support and had a network of HPs that they could turn to for advice or care if they believed it necessary. Expertise in SCI seemed to be crucial especially for the Selectives, as some participants stated that they preferred to find solutions on their own rather than turning to HPs who had no expertise (e.g. general practitioners) In line with their preference for delegating the responsibility of prevention, the Delegators seemed to prefer more supervision (e.g. regular checkups in the outpatient clinic, home visits from the specialized counseling service).	1. Different ideas of responsibility for self-management. a) guidance of caregivers or health professionals b) found solutions themselves (problem-solvers)

ICF – International Classification of Functioning, Disability, and Health, CHF – chronic heart failure, HF – heart failure, CR – cardiac rehabilitation, T2D – type two diabetes, SCI – spinal cord injury, PI – pressure injury

References

1. Audulv Å. The over time development of chronic illness self-management patterns: a longitudinal qualitative study. BMC public health. 2013;13:452.

2. Bowling CB, Vandenberg AE, Phillips LS, McClellan WM, Johnson TM, 2nd, Echt KV. Older Patients' Perspectives on Managing Complexity in CKD Self-Management. Clinical journal of the American Society of Nephrology : CJASN. 2017;12(4):635-43.

3. 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. Australian Health Review. 2013;37(1):19-25.

4. Dixon A, Hibbard J, Tusler M. How do People with Different Levels of Activation Self-Manage their Chronic Conditions? The patient. 2009;2(4):257-68.

5. Duguay C, Gallagher F, Fortin M. The experience of adults with multimorbidity: a qualitative study. Journal of comorbidity. 2014;4:11-21.

6. Fuller BG, Stewart Williams JA, Byles JE. Active living—the perception of older people with chronic conditions. Chronic illness. 2010;6(4):294-305.

7. Gardsten C, Blomqvist K, Rask M, Larsson Å, Lindberg A, Olsson G. Challenges in everyday life among recently diagnosed and more experienced adults with type 2 diabetes: A multistage focus group study. Journal of clinical nursing. 2018;27(19-20):3666-78.

8. Gary R. Self-care practices in women with diastolic heart failure. Heart & Lung. 2006;35(1):9-19.

9. Haverhals LM, Lee CA, Siek KA, Darr CA, Linnebur SA, Ruscin JM, et al. Older adults with multi-morbidity: medication management processes and design implications for personal health applications. Journal of medical Internet research. 2011;13(2):e44.

10. Janevic MR, Ellis KR, Sanders GM, Nelson BW, Clark NM. Self-management of multiple chronic conditions among African American women with asthma: a qualitative study. Journal of Asthma. 2014;51(3):243-52.

11. Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. Patient education and counseling. 2005;57(3):300-7.

12. Majeed-Ariss R, Jackson C, Knapp P, Cheater FM. British-Pakistani women's perspectives of diabetes self-management: the role of identity. Journal of clinical nursing. 2015;24(17-18):2571-80.

13. Mickelson RS, Willis M, Holden RJ. Medication-related cognitive artifacts used by older adults with heart failure. Health Policy and Technology. 2015;4(4):387-98.

14. Mphwanthe G, Carolan M, Earnesty D, Weatherspoon L. Perceived barriers and facilitators to diet and physical activity among adults diagnosed with type 2 diabetes in Malawi. Global Public Health.

15. Munce SE, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. BMC neurology. 2014;14:48.

16. O'Conor R, Martynenko M, Gagnon M, Hauser D, Young E, Lurio J, et al. A qualitative investigation of the impact of asthma and self-management strategies among older adults. The Journal of asthma : official journal of the Association for the Care of Asthma. 2017;54(1):39-45.

17. Paterson B. Myth of empowerment in chronic illness. Journal of advanced nursing. 2001;34(5):574-81.

18. Salim H, Young I, Lee PY, Shariff-Ghazali S, Pinnock H. 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. 2021.

19. Steinman L, Heang H, van Pelt M, Ide N, Cui H, Rao 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 and uHealth. 2020;8(4):e13536.

20. Bovenkamp HM, Dwarswaard J. The complexity of shaping self-management in daily practice. Health Expectations. 2017;20(5):952-60.

21. Williams A, Manias E, Cross W, Crawford K. Motivational interviewing to explore culturally and linguistically diverse people's comorbidity medication self-efficacy. Journal of clinical nursing. 2015;24(9-10):1269-79.

22. Zanini C, Brach M, Lustenberger N, Scheel-Sailer A, Koch HG, Stucki G, 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. Journal of Spinal Cord Medicine. 2020;43(2):247-56.

Supplementary Table 2. Themes and subthemes

Theme	Subtheme	Articles contributing to the themes
Environment support	*Family and cultural norms*	• Bowling et al. • Gary et al. • Jerant et al. • Majeed et al. • Mphwanthe et al. • Munce et al. • Williams et al.
	Health professionals and guiding communication	• Bowling et al. • Dixon et al. • Haverhals et al. • Jerant et al. • Mickelson et al. • Paterson et al. • Van de Bovenkamp et al. • Zanini et al.
	Society and chronic disease perceptions	• Duguay et al. • Mphwanthe et al. • Salim et al.

Comprehension gap	*Reading the body*	• Audulv et al. • Corcoran et al. • Fuller et al. • Gardsten et al. • Haverhals et al. • Janevic et al. • O'Conor et al. • Steinman et al.
	Applying information	• Dixon et al. • Gardsten et al. • Jerant et al.

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

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	
ABSTRACT			
Structured summary	2	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.	
INTRODUCTION			
Rationale	3	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.	
Objectives	4	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.	
METHODS			
Protocol and registration	5	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.	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	
Information sources*	7	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.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	
Data charting process‡	10	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.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	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).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	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.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	
DISCUSSION			
Summary of evidence	19	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.	
Limitations	20	Discuss the limitations of the scoping review process.	
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	
FUNDING			
Funding	22	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.	

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 by Arksey and O'Malley (6) and Levac 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).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

BMJ Open

Factors influencing the integration of self-management in daily life routines in chronic conditions: A scoping review of qualitative evidence.

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-066647.R2
Article Type:	Original research
Date Submitted by the Author:	29-Nov-2022
Complete List of Authors:	Qama, Enxhi; Swiss Paraplegic Research, Rubinelli , Sara ; Swiss Paraplegic Research, Diviani, Nicola; Swiss Paraplegic Research
Primary Subject Heading:	Communication
Secondary Subject Heading:	Qualitative research, Rehabilitation medicine
Keywords:	QUALITATIVE RESEARCH, General diabetes < DIABETES & ENDOCRINOLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, SOCIAL MEDICINE, Heart failure < CARDIOLOGY

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]

[1] Swiss Paraplegic Research, Nottwil, Switzerland

[2] Department of Health Sciences and Medicine, University of Lucerne, Lucerne, Switzerland

* Corresponding author at:
Swiss Paraplegic Research
Person-centered Healthcare & Health Communication Group
Guido A. Zäch Strasse 4
6207 Nottwil
Switzerland
+41 41 939 65 78
enxhi.qama@paraplegie.ch

sara.rubinelli@paraplegie.ch
nicola.diviani@paraplegie.ch

Keywords: social medicine; qualitative research; quality in healthcare; general diabetes, heart failure

Word count: 3574

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 behaviors 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: PubMed, Web of Science, Cinahl, and PsycInfo

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 was synthesized and analyzed thematically. PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist was used for reporting the steps.

Results: Twenty-two studies were included. The thematic analysis brought up two overreaching 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.

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 made 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.

1. 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 behaviors 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 changes (11) is considered to facilitate self-management. (13) They suggest that patients need scheduling and prioritization skills in their familial and societal roles, such as work or special occasions like holidays and vacations. (11, 13). To better conceptualize 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 synthesize 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) says 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 summarizing 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.

2. Methods

To reach the aforementioned objective we followed Arksey and O'Malley's methodology for conducting a scoping review. (18) We adopted the PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist for reporting the steps (see Supplementary Material, PRISMA-ScR Checklist). (19)

2.1 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 familial and societal roles in people living with chronic conditions?

RQ2: How do these factors influence this process?

2.2 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 function (20) 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 characterized by a great amount of unpredictability and considered life-threating (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)."

2.3 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.

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.

2.4 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 (i.e.*' 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 Supplementary Figure 1. Prisma Flow chart).

2.5 Charting the data

Two reviewers prepared a standardized table to extract relevant information from eligible articles. Data extraction was conducted independently by the same reviewers. Supplementary 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. Supplementary Table 2 summarized 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 with author's chosen quotes for illustration.

2.6 Collating, summarizing 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 Supplementary 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?

2.7 Patient and public involvement

None

3. Results

3.1 Study characteristics

After screening the abstracts of 9,360 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 Supplementary Figure 1. The studies were conducted between 2001(42) and 2021 (43). The majority (n = 9) are from the United States (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 United Kingdom (37), Malawi (39), the Netherlands (45), and Malaysia (43). There are twenty qualitative studies

(26-34, 36, 37, 39-47) and two 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 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). (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) Fours 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 behaviors over time (26).

3.2 Thematic analysis

The synthesis of results yielded two main overreaching 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*.

3.2.1 Environment support

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

3.2.1.1 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 emphasize that sometimes gender roles (e.g. spouses and mothers) within a family could jeopardize self-care (36, 37, 46). They feel the pressure of having to choose and prioritize (27, 33, 39, 46) between their self-management routines or family needs (46): "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 prioritized their care over their own at times". (46)

3.2.1.2 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 physicians (36): "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 environment (38): "cognitive artifacts 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 them (42): "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)

3.2.1.3 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 settings (43): "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) Stigmatizing events like distancing attitudes (30) or unpleasant reactions from friends or peers (43), inevitably influenced self-management and brought out feelings of isolation (30): "'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)

3.2.2 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.

3.2.2.1 Reading the body

This theme describes the difficulties that patients experience in recognizing 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 result (44): "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 cues (28); in more independent cases these knowledge gaps could make patients clueless of the fact that a good life can be achieved with proper self-management (41): "Patients had accepted a level of 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". (41)

3.2.2.2 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 example (32): "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)

4. Discussion and further research

4.1 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 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) depression, (49) or spinal cord injury. (50) More studies should explore methods used by health professionals to build personalized 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 conditions (51-54) 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 conceptualization 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 error (59-61) 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)

4.2 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 conceptualization of the search strategy. We may have neglected some aspects of the routines of self-management, since there is no clear conceptualization 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 synthesizing evidence on a broad range of chronic diseases and self-management activities. Although it can offer a strong basis for generalization, more in-depth research on individual conditions or self-management activities and recommendations should be carried out.

5. 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 personalized interventions for patient education in chronic condition self-management.

Contributors

All authors contributed to the conceptualization 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.

Funding statement

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

Competing Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Statement

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

Disclaimer

The funding source had no role in the study's conceptualization, decision to publish, or preparation of the manuscript.

Patient consent

Not required

Data sharing statement

All data relevant to the study are included in the article or uploaded as supplementary information.

Exclusive license statement

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive

licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in BMJ Open and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

For peer review only

References

1. Richard AA, Shea K. Delineation of Self-Care and Associated Concepts. Journal of Nursing Scholarship. 2011;43(3):255-64.

2. Van de Velde D, De Zutter F, Satink T, Costa U, Janquart S, Senn D, et al. Delineating the concept of self-management in chronic conditions: a concept analysis. BMJ open. 2019;9(7):e027775.

3. Goodman RA, Posner SF, Huang ES, Parekh AK, Koh HK. Peer reviewed: defining and measuring chronic conditions: imperatives for research, policy, program, and practice. Preventing chronic disease. 2013;10.

4. O'Halloran J, Miller GC, Britt H. Defining chronic conditions for primary care with ICPC-2. Family practice. 2004;21(4):381-6.

5. Shaul MP. From early twinges to mastery: the process of adjustment in living with rheumatoid arthritis. Arthritis & Rheumatism: Official Journal of the American College of Rheumatology. 1995;8(4):290-7.

6. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. Journal of Nursing Scholarship. 2012;44(2):136-44.

7. Robinson CA. Managing life with a chronic condition: The story of normalization. Qualitative health research. 1993;3(1):6-28.

8. Kwasnicka D, Dombrowski SU, White M, Sniehotta F. Theoretical explanations for maintenance of behaviour change: a systematic review of behaviour theories. Health psychology review. 2016;10(3):277-96.

9. Sniehotta FF, Schwarzer R, Scholz U, Schüz B. Action planning and coping planning for long-term lifestyle change: theory and assessment. European Journal of Social Psychology. 2005;35(4):565-76.

10. Mackey LM, Doody C, Werner EL, Fullen B. Self-Management Skills in Chronic Disease Management: What Role Does Health Literacy Have? Medical Decision Making. 2016;36(6):741-59.

11. Koch G, Wakefield BJ, Wakefield DS. Barriers and Facilitators to Managing Multiple Chronic Conditions: A Systematic Literature Review. Western journal of nursing research. 2014;37(4):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. Canadian Family Physician. 2014;60(12):1123-33.

13. Schulman-Green D, Jaser SS, Park C, Whittemore R. A metasynthesis of factors affecting self-management of chronic illness. Journal of advanced nursing. 2016;72(7):1469-89.

14. Russell S, Ogunbayo OJ, Newham JJ, Heslop-Marshall K, Netts P, Hanratty B, et al. Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals. NPJ primary care respiratory medicine. 2018;28(1):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(1):320.

16. Miles C, Arden-Close E, Thomas M, Bruton A, Yardley L, Hankins M, et al. Barriers and facilitators of effective self-management in asthma: systematic review and thematic synthesis of patient and healthcare professional views. NPJ primary care respiratory medicine. 2017;27(1):57.

17. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. International journal of evidence-based healthcare. 2015;13(3):141-6.

18. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International journal of social research methodology. 2005;8(1):19-32.

19. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Annals of internal medicine. 2018;169(7):467-73.

20. Botvin GJ, Griffin KW, Scheier LM. Developmental trajectories of self-management skills and adolescent substance use. Salud y drogas. 2009;9(1):15-37.

21. Trivedi MH, Lin E, Katon WJ. Consensus recommendations for improving adherence, self-management, and outcomes in patients with depression. CNS spectrums. 2007;12(8 Suppl 13):1-27.

22. Chattopadhyay S, Karlsson J, Mañas A, Kanzaki R, Fredlund E, Murphy AJ, et al. Evolutionary unpredictability in cancer model system. bioRxiv. 2022:2022.06.01.494285.

23. Mansky PJ, Wallerstedt DB. Complementary medicine in palliative care and cancer symptom management. The Cancer Journal. 2006;12(5):425-31.

24. Harding R. Palliative care as an essential component of the HIV care continuum. The lancet HIV. 2018;5(9):e524-e30.

25. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.

26. Audulv Å. 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, McClellan WM, Johnson TM, 2nd, Echt KV. Older Patients' Perspectives on Managing Complexity in CKD Self-Management. Clinical journal of the American Society of Nephrology : CJASN. 2017;12(4):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. Australian Health Review. 2013;37(1):19-25.

29. Dixon A, Hibbard J, Tusler M. How do People with Different Levels of Activation Self-Manage their Chronic Conditions? The patient. 2009;2(4):257-68.

30. Duguay C, Gallagher F, Fortin M. The experience of adults with multimorbidity: a qualitative study. Journal of comorbidity. 2014;4:11-21.

31. Fuller BG, Stewart Williams JA, Byles JE. Active living—the perception of older people with chronic conditions. Chronic illness. 2010;6(4):294-305.

32. Gardsten C, Blomqvist K, Rask M, Larsson Å, Lindberg A, Olsson G. Challenges in everyday life among recently diagnosed and more experienced adults with type 2 diabetes: A multistage focus group study. Journal of clinical nursing. 2018;27(19-20):3666-78.

33. Gary R. Self-care practices in women with diastolic heart failure. Heart & Lung. 2006;35(1):9-19.

34. Haverhals LM, Lee CA, Siek KA, Darr CA, Linnebur SA, Ruscin JM, et al. Older adults with multi-morbidity: medication management processes and design implications for personal health applications. Journal of medical Internet research. 2011;13(2):e44.

35. Janevic MR, Ellis KR, Sanders GM, Nelson BW, Clark NM. Self-management of multiple chronic conditions among African American women with asthma: a qualitative study. Journal of Asthma. 2014;51(3):243-52.

36. Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. Patient education and counseling. 2005;57(3):300-7.

37. Majeed-Ariss R, Jackson C, Knapp P, Cheater FM. British-Pakistani women's perspectives of diabetes self-management: the role of identity. Journal of clinical nursing. 2015;24(17-18):2571-80.

38. Mickelson RS, Willis M, Holden RJ. Medication-related cognitive artifacts used by older adults with heart failure. Health Policy and Technology. 2015;4(4):387-98.

39. Mphwanthe G, Carolan M, Earnesty D, Weatherspoon L. Perceived barriers and facilitators to diet and physical activity among adults diagnosed with type 2 diabetes in Malawi. Global Public Health.

40. Munce SE, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. BMC neurology. 2014;14:48.

41. O'Conor R, Martynenko M, Gagnon M, Hauser D, Young E, Lurio J, et al. A qualitative investigation of the impact of asthma and self-management strategies among older adults. The Journal of asthma : official journal of the Association for the Care of Asthma. 2017;54(1):39-45.

42. Paterson B. Myth of empowerment in chronic illness. Journal of advanced nursing. 2001;34(5):574-81.

43. Salim H, Young I, Lee PY, Shariff-Ghazali S, Pinnock H. 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. 2021.

44. Steinman L, Heang H, van Pelt M, Ide N, Cui H, Rao 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 and uHealth. 2020;8(4):e13536.

45. Bovenkamp HM, Dwarswaard J. The complexity of shaping self-management in daily practice. Health Expectations. 2017;20(5):952-60.

46. Williams A, Manias E, Cross W, Crawford K. Motivational interviewing to explore culturally and linguistically diverse people's comorbidity medication self-efficacy. Journal of clinical nursing. 2015;24(9-10):1269-79.

47. Zanini C, Brach M, Lustenberger N, Scheel-Sailer A, Koch HG, Stucki G, 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. Journal of Spinal Cord Medicine. 2020;43(2):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 research and clinical practice. 2013;100(2):145-61.

49. Gellis ZD, Kenaley B. Problem-solving therapy for depression in adults: a systematic review. Research on Social Work Practice. 2008;18(2):117-31.

50. Elliott TR, Shewchuk RM, Richards JS. Caregiver social problem-solving abilities and family member adjustment to recent-onset physical disability. Rehabilitation Psychology. 1999;44(1):104-23.

51. Crespo C, Santos S, Canavarro MC, Kielpikowski M, Pryor J, Féres-Carneiro T. Family routines and rituals in the context of chronic conditions: A review. International Journal of Psychology. 2013;48(5):729-46.

52. Gallant MP, Spitze GD, Prohaska TR. Help or Hindrance? How Family and Friends Influence Chronic Illness Self-Management among Older Adults. Research on aging. 2007;29(5):375-409.

53. Satink T, Josephsson S, Zajec J, Cup EH, de Swart BJ, Nijhuis-van der Sanden MW. Negotiating role management through everyday activities: narratives in action of two stroke survivors and their spouses. Disability and rehabilitation. 2016;38(24):2354-64.

54. Whitehead L, Jacob E, Towell A, Abu-Qamar M, Cole-Heath A. The role of the family in supporting the self-management of chronic conditions: A qualitative systematic review. Journal of clinical nursing. 2018;27(1-2):22-30.

55. Anderson RM. Patient empowerment and the traditional medical model: a case of irreconcilable differences? Diabetes care. 1995;18(3):412-5.

56. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. Jama. 2002;288(19):2469-75.

57. Audulv Å, Asplund K, Norbergh K-G. The integration of chronic illness self-management. Qualitative health research. 2012;22(3):332-45.

58. Hörnsten Å, Jutterström L, Audulv Å, Lundman B. A model of integration of illness and self-management in type 2 diabetes. Journal of Nursing and Healthcare of Chronic Illness. 2011;3(1):41-51.

59. Deshaies K, Hernandez CA. Integration: a phenomenon to explore in chronic nonmalignant pain (CNP). Pain Management Nursing. 2011;12(1):2-14.

60. Whittemore R, Chase SK, Mandle CL, Roy C. Lifestyle change in type 2 diabetes a process model. Nursing research. 2002;51(1):18-25.

61. Diviani N, Obrenovic J, Montoya CL, Karcz K. Disentangling health information appraisal competence: Results from an interdisciplinary scoping review and online consultation among Swiss stakeholders. PloS one. 2020;15(7):e0235474.

62. Mickelson RS, Unertl KM, Holden RJ. Medication Management: The Macrocognitive Workflow of Older Adults With Heart Failure. JMIR human factors. 2016;3(2):e27.

63. Dickson VV, Buck H, Riegel B. Multiple comorbid conditions challenge heart failure self-care by decreasing self-efficacy. Nursing research. 2013;62(1):2-9.

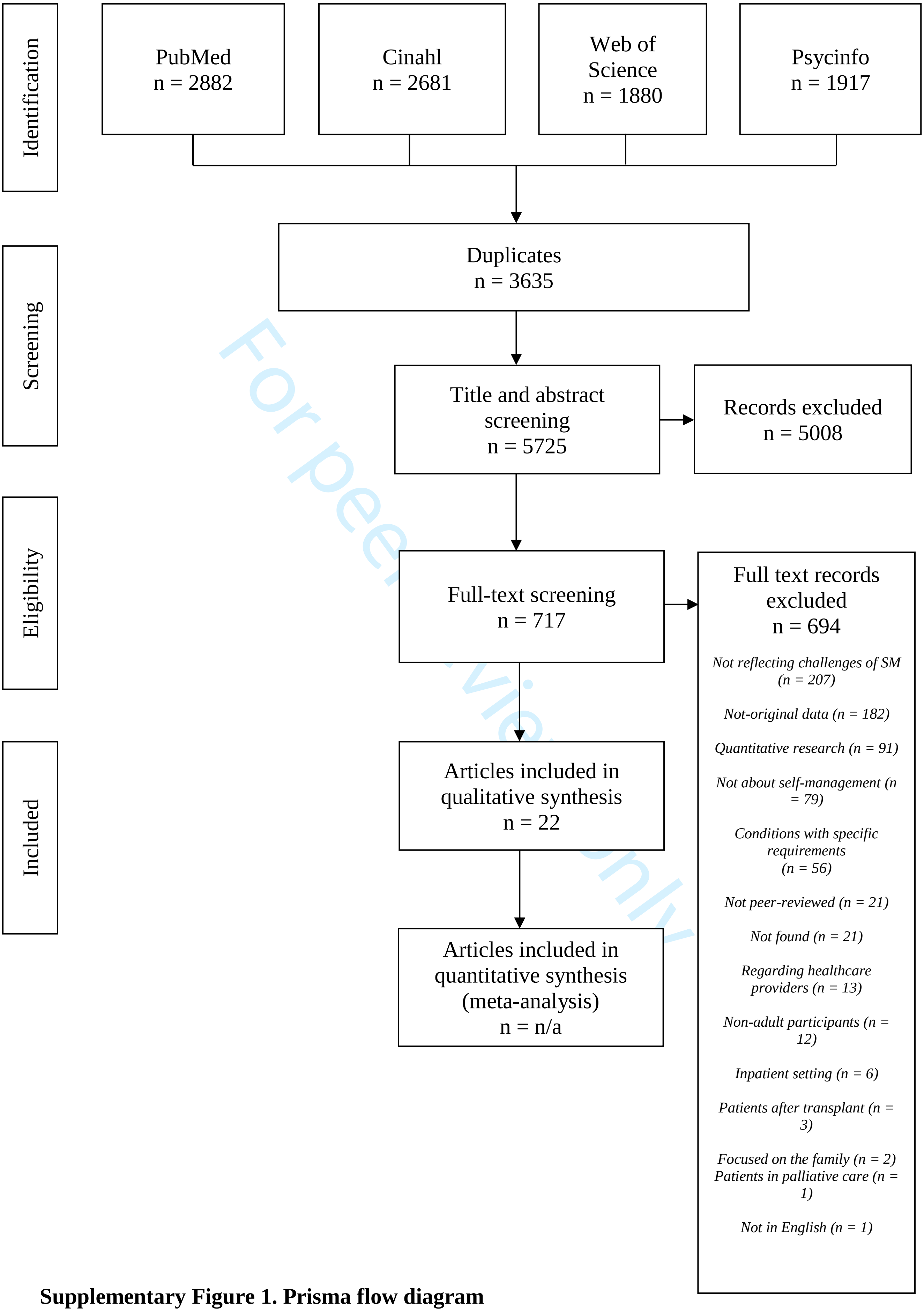
64. Vest JR, Gamm LD. Health information exchange: persistent challenges and new strategies. Journal of the American Medical Informatics Association. 2010;17(3):288-94.

65. Hermanowicz JC. The longitudinal qualitative interview. Qualitative sociology. 2013;36(2):189-208.

66. Saldaña J. Longitudinal qualitative research: Analyzing change through time: Rowman Altamira; 2003.

67. Lucas PJ, Baird J, Arai L, Law C, Roberts HM. Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. BMC medical research methodology. 2007;7(1):1-7.

68. Paterson BL, Russell C, Thorne S. Critical analysis of everyday self-care decision making in chronic illness. Journal of Advanced Nursing (Wiley-Blackwell). 2001;35(3):335-41.



Supplementary Figure 1. Prisma flow diagram

Supplementary Table 1. Characteristics of the included studies

Author	Year	Country	Participants	Disease	Method	Self-management activity/recommendation	Aim
Audulv A (25)	2013	Sweden	21	Ischemic heart disease, rheumatic disease, chronic renal disease, inflammatory bowel disease, multiple sclerosis, diabetes	Qualitative	Exercise	To describe the different chronic illness self-management behavior patterns that individuals develop and maintain over time.
Bowling C. B (26)	2017	US	30	Chronic kidney disease	Qualitative	Diet and others	To understand the relationship among factors facilitating or impeding chronic kidney disease self-management in older adults.
Corcoran K. J (27)	2013	Australia	40	Chronic heart failure, diabetes, chronic	Qualitative	Managing symptoms	To identify the major disease-specific experiences of individuals living with diabetes, chronic heart failure, chronic obstructive pulmonary disease.

				obstructive pulmonary disease			
Dixon A (28)	2009	US	27	High cholesterol, arthritis, back pain or sciatica, cancer, diabetes, heart disease, depression, other	Qualitative	Exercise and other	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.
Duguay C (29)	2014	Canada	11	Hypertension, hyperlipidemia, diabetes, coronary artery disease, obesity, arthritis, chronic obstructive pulmonary disorder	Qualitative	Managing symptoms, managing medications	To describe the fundamental structure of adults' experience with multimorbidity.
Fuller B.G (30)	2010	Australia	99	Older people with and without chronic heart or lung conditions	Qualitative	Exercise, managing symptoms	To describe and understand factors which enhance and impede participation in physical activity for older adults with and without chronic illness.

Gardsten C (31)	2018	Sweden	11	Diabetes	Qualitative	Recognizing and managing symptoms, exercise, diet	To identify perceived challenges related to self-management among recently diagnosed adults and those with longer experience of type 2 diabetes.
Gary R (32)	2006	US	32	Diastolic heart failure	Qualitative	Diet	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.
Haverhals L (33)	2011	US	32 patients, 2 caregivers	Older people with one or more chronic medical conditions	Qualitative	Managing medication	To understand the medication self-management issues faced by older adults and caregivers that can be addressed by an electronic PHA (Personal health applications).
Janevic M.R (34)	2013	US	25	Asthma plus others	Mixed method	Recognizing and managing symptoms	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.
Jerant A.F (35)	2005	US	54	Diabetes, arthritis, depression, chronic heart	Qualitative	Managing symptoms, medication, diet	To elicit perceived barriers to active self-management and to

				failure, asthma, other			accessing self-management support resources.
Majeed-Ariss R (36)	2015	UK	15	Diabetes	Qualitative	Diet and others	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.
Mickelson R (37)	2015	US	30	Heart failure	Mixed method	Managing medication	To examine how older adult patients with heart failure use cognitive artifacts for medication management.
Mphwanthe G (38)	2020	Malawi	39	Diabetes	Qualitative	Diet, exercise	To identify barriers, facilitators and support for diet and physical activity among adults with type 2 diabetes.
Munce S.E (39)	2014	Canada	26	Spinal cord injury	Qualitative		To understand the perceived facilitators and barriers to self-management to prevent secondary complications.
O'Conor R (40)	2016	US	31	Asthma	Qualitative	Managing symptoms	To understand their experience with assuming self-management roles for their asthma.
Paterson B (41)	2001	Canada	22	Diabetes	Qualitative		To investigate self-care decision making in diabetes.

Salim H (42)	2021	Malaysia	26	Asthma	Qualitative	Managing symptoms	To explore how people with limited health literacy understand asthma and undertake self-management practices.
Steinman L (43)	2020	US	70	Diabetes and hypertension	Qualitative	Exercise, managing symptoms	To understand the facilitators and barriers to chronic disease management and the acceptability, appropriateness, and feasibility of mHealth.
Van de Bovenkamp H (44)	2017	Netherland	26	Rheumatic disease, diabetes, kidney failure, glaucoma, gout, kidney transplantation, heart failure, hearing disability, vision problems, cancer, tuberculosis, immune disease, high blood pressure,	Qualitative	Managing medication	To explore the way patient self-management is shaped in practice, including the implications of the difficulties encountered.

				high cholesterol, gastric bypass surgery			
Williams A (45)	2014	Australia	26	Diabetes, chronic kidney disease and cardiovascular disease	Qualitative	Managing medication	To examine the perceptions of a group of culturally and linguistically diverse participants with the comorbidities.
Zanini C (46)	2018	Switzerland	20	Spinal cord injury	Qualitative	Managing complications	To identify styles of prevention that individuals with spinal cord injury adopt to deal with the risk of developing pressure injuries.

Supplementary Table 2. Extracts from the included studies and codes

Author	Extract	Codes
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.	2. Difficulty scheduling and fitting exercises around work, domestic tasks and social engagement.
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).	1. Physical limitations are not managed enough to be able to perform other activities in daily life (work, social). a) not being invited in trips b) accomplish activities alone to avoid social pressure.
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.	1. Not understood the intensity and duration of the physical activity. No skills how to measure activity levels
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	1. Difficult to understand, read the symptoms. Also, how do daily routines influence symptoms?

	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.	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 an apply in in individual circumstances b) wished more practical information from health professionals
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

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 met 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.	3. Physical limitations are not managed enough to be able to attend social engagements
Majeed-Aris et al. (36)	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	1. Wives, mothers, and daughters-in-law prioritize family needs first even though it affects their health. a) sometimes the husband is also sick b) sometimes the family is not supportive c) sometimes children are young and need care

	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.	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
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. Difficult to follow diet recommendations in another circumstances (e.g. travel, weddings). a) ate something else b) modified the portions c) ate the available food, prioritized family 2. Challenge in performing exercise because of fear of public ridicule. a) family not supportive b) society stigma

	[once in a while] dance in my bedroom as part of exercise, because my children and other family members including the neighbors laugh at me when I dance as exercise outside the house' Indeed, neighbors disappoint us. One day a neighbor said, 'Why do you do all the household chores as if you don't have children? But for me this is part of my exercise'.	
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.	a) jargon b) not relevant to their unique environment and situation
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.	1. Stigmatizing events were difficult and impacted self-management.
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?	1. Knowledge gaps included frequency, intensity, and duration of physical activity and dietary modifications. Lacked the skills to incorporate the recommendation to daily routines .

	Challenges to incorporating recommended dietary changes into their daily routine included that household meals are prepared by other household members and that 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.	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 .
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).	1. Prioritizing family need over self-care.
Zanini et al. (46)	What distinguished the Delegators from the Thoughtfuls and the Selectives was their preference for passive (e.g. air-flow bed) versus active preventive measures (e.g. skin inspection), their tendency to act under the guidance of caregivers and not on personal initiative, and their preference for handing over responsibility prevention to others (e.g. homecare service) Additionally, the Delegators had high expectations from the performance of assistive devices (e.g. no need to change position in bed) and could consequently be annoyed if a PI developed despite their use. Selectives reported contacting experts for timely support and had a network of HPs that they could turn to for advice or care if they believed it necessary. Expertise in SCI seemed to be crucial especially for the Selectives, as some participants stated that they preferred to find solutions on their own rather than turning to HPs who had no expertise (e.g. general practitioners) In line with their preference for delegating the responsibility of prevention, the Delegators seemed to prefer more supervision (e.g. regular checkups in the outpatient clinic, home visits from the specialized counseling service).	1. Different ideas of responsibility for self-management. a) guidance of caregivers or health professionals b) found solutions themselves (problem-solvers)

ICF – International Classification of Functioning, Disability, and Health, CHF – chronic heart failure, HF – heart failure, CR – cardiac rehabilitation, T2D – type two diabetes, SCI – spinal cord injury, PI – pressure injury

Supplementary Table 3. Themes and subthemes

Theme	Subtheme	Articles contributing to the themes
Environment support	*Family and cultural norms*	• Bowling et al. • Gary et al. • Jerant et al. • Majeed et al. • Mphwanthe et al. • Munce et al. • Williams et al.
	Health professionals and guiding communication	• Bowling et al. • Dixon et al. • Haverhals et al. • Jerant et al. • Mickelson et al. • Paterson et al. • Van de Bovenkamp et al. • Zanini et al.
	Society and chronic disease perceptions	• Duguay et al. • Mphwanthe et al. • Salim et al.

Comprehension gap	*Reading the body*	• Audulv et al. • Corcoran et al. • Fuller et al. • Gardsten et al. • Haverhals et al. • Janevic et al. • O'Conor et al. • Steinman et al.
	Applying information	• Dixon et al. • Gardsten et al. • Jerant et al.

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

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	
ABSTRACT			
Structured summary	2	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.	
INTRODUCTION			
Rationale	3	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.	
Objectives	4	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.	
METHODS			
Protocol and registration	5	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.	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	
Information sources*	7	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.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	
Data charting process‡	10	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.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	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).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	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.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	
DISCUSSION			
Summary of evidence	19	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.	
Limitations	20	Discuss the limitations of the scoping review process.	
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	
FUNDING			
Funding	22	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.	

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 by Arksey and O'Malley (6) and Levac 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).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.