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REVIEW

# Patient perspectives on factors associated with enrollment and retention in chronic disease self-management programs: a systematic review

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**Background:** Challenges exist when enrolling and retaining chronic disease patients in self-management programs. Exploring patient perspectives on participating in self-management programs may enhance study enrollment and retention and thereby improve health outcomes. Limited review research has synthesized patient perspectives on intrapersonal and sociocontextual factors influencing participation in chronic disease self-management programs.

**Objective:** To synthesize empirical qualitative research exploring intrapersonal (ie, predisposing) and sociocontextual (ie, predisposing, enabling, need) factors influencing patient enrollment and retention in chronic disease self-management programs.

**Method:** A systematic literature review was conducted using Garrard's Matrix Method to retrieve articles published between 1997 and 2015 from electronic databases (PsycINFO, CINAHL, MEDLINE). Andersen's Behavioral Model of Health Services Use was used to synthesize data according to intrapersonal and sociocontextual factors impacting participation in self-management programs.

**Results:** Thirteen (N=13) qualitative studies met inclusion criteria. Most studies focused on cardiovascular (n=4; 30.76%) and chronic lower respiratory (n=3; 23.07%) diseases. Predisposing factors such as limited disease-specific knowledge, negative outcome expectations of self-management, and confusion about comorbidity self-care negatively influenced the decision to participate. Enabling factors, including opportunities for social support, positively influenced the decision to participate in self-management programs. Scheduling conflicts negatively influenced patient participation. Beliefs that current health care was sufficient deterred patients from participating in self-management programs.

**Discussion:** Making perceived benefits of participating in chronic disease self-management programs more salient to patients and their health care providers has the potential to enhance patient enrollment and retention. Researchers and clinicians may begin to improve patient participation in chronic disease self-management programs by implementing patient-centered education to increase disease-specific knowledge and an understanding of the recruitment, enrollment, and retention process in research. Future research should explore the intrapersonal and sociocontextual factors influencing patient participation in self-management programs that offer enhanced accessibility and social support from peers and caregivers.

**Keywords:** chronic disease, self-management, patient enrollment, patient retention

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## Introduction

Chronic diseases, including heart disease, cancer, type 2 diabetes, and chronic lower respiratory conditions, are the leading causes of death worldwide.[1] The rising prevalence of chronic disease poses a major threat to public and financial health on a global scale. Worldwide estimates suggest that 60% of deaths are attributable to chronic

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disease annually,[2] with total global economic losses due to chronic disease expected to reach $7 trillion dollars by 2025.[3] Although the health care burden of chronic disease exists worldwide, vulnerable populations such as those who are older,[4] belong to racial/ethnic minority groups,[5] who live in a rural or remote geographic locations,[6] and who possess limited health literacy skills,[7,8] report a higher prevalence of chronic disease and experience greater difficulty managing their symptoms. It is estimated that ~$11.2 billion will be required to implement systematic programs that alleviate the burden of chronic disease.[1]

Advancements in health care technology have increased the availability and accessibility of services designed to assist patients in self-managing their chronic conditions and associated symptoms.[9] Chronic disease self-management programs are defined as planned learning experiences intended to enhance patient self-efficacy, health status, and behavioral skills necessary to effectively manage lifestyle changes, such as medication adherence, physical activity, and making healthy dietary decisions.[10–12] Self-management programs have reduced the frequency and need for emergency room visits and hospital admissions.[13] Within chronic disease self-management, emphasis is placed on the patient's role in treating his or her own disease through symptom monitoring and management, which is often individualized, goal-oriented, and facilitated in collaboration with health care providers.[10–12] Health providers and health educators are often involved in developing, delivering, and evaluating chronic disease self-management programs designed to improve health behaviors, psychological health status, and self-efficacy for symptom management.[14] The availability and accessibility of comprehensive and high-quality chronic disease self-management programs that actively involve patients in the health decision-making process is important to reduce health inequities caused by poorly managed, severe chronic disease symptoms.[15]

Research suggests positive associations exist between participation in chronic disease self-management and perceived social support and self-efficacy.[16–18] However, current literature provides conflicting evidence regarding the long-term benefits of participating in chronic disease self-management programs.[4,19–22] Patients with advanced stages of chronic disease (eg, type 2 diabetes, chronic lower respiratory conditions, cancer) generally experience severe symptoms and high rates of premature mortality,[10,23] which partially contributes to small sample sizes (eg, 20–30)[19,24,25] and high attrition in self-management programs.[23,26,27] However, researchers argue that understanding reasons for patients choosing to enroll/not enroll and participate in self-management can be determined by exploring patient attitudes and beliefs on factors that affect recruitment and retention.[28,29]

Existing research exploring reasons for low enrollment and high attrition in chronic disease self-management programs has primarily focused on quantitative measures[30,31] to draw conclusions based on associations between patients' demographic factors, patient/provider time spent participating in self-management programs, and using patient feedback at follow-up. Verevkina et al[30] found that low baseline self-efficacy to self-manage chronic disease, younger patient age, and weekday program sessions were significantly associated with high patient attrition from chronic disease self-management programs. Laws et al[31] found that high psychological distress and an unemployment status predicted high patient enrollment and retention, and scheduling conflicts were significantly associated with high attrition rates. Although these findings are important to understand patient enrollment and retention, qualitatively exploring the sociocontextual factors that influence patient participation in self-management programs may better inform recruitment and program strategies that optimize patient enrollment and retention.

Andersen's Behavioral Model of Health Services Use (BMHSU)[32–34] posits that there are a number of intrapersonal and sociocontextual factors influencing a patient's decision and ability to use health care services, such as chronic disease self-management programs. Figure 1 illustrates the BMHSU, which attempts to explain "why" and "how" patients use health care services using three explanatory, intrapersonal (ie, predisposing), and sociocontextual (ie, enabling, reinforcing) factors. In the BMHSU, "predisposing factors" are biological and contextual variables that prompt or prevent an individual to enroll and/or participate in health services. "Enabling factors" are financial and organizational variables that influence an individual's ability or decision to obtain health services. These factors include access to health insurance, geographic location, and family support. The final set of factors, "need factors", involves both a patient and provider's perception about the status and diagnosis of the patient's illness or health concern (eg, patients' perceived symptoms and health-related quality of life). Ultimately, the BMHSU postulates that need factors are the most immediate causal factor influencing a patient's decision to enroll and use health services. The BMHSU has been used as a framework to: 1) understand how and why uninsured patients with chronic disease use hospital services and medications;[35] 2) explore relationships between use of health care services among medically underserved and uninsured patients living with chronic disease;[36] and

3) identify factors that contribute to patient recruitment and retention in type 2 diabetes self-management.[37]

It is unclear what challenges and opportunities exist with regard to enrollment and retention in self-management programs for patients simultaneously living with multiple chronic conditions. In order to optimize patient enrollment and retention in self-management programs, there is a need to consider the voice of patients when exploring the factors affecting participation in chronic disease self-management. By actively engaging and eliciting feedback from patients about their perspectives on participation in chronic disease self-management programs, there is potential to create higher-quality interventions that are more sustainable over long periods of time.[38,39] However, understanding which attributes of self-management programs are most conducive to patient participation is currently unknown. Because the economic burden of poorly managed chronic disease is expected to continue to increase over the next decade, it will be important to identify up-to-date intrapersonal and sociocontextual factors that promote patient recruitment and retention in chronic disease self-management.

Unlike in quantitative research, qualitative methods aim to understand select phenomena and associations between variables by proposing open-ended questions, discussions, and observation in naturalistic settings.[40] Synthesizing qualitative research can provide researchers and clinicians with rich, comprehensive data on complex causal mechanisms explaining how and why patients living with chronic disease choose to enroll and participate in self-management programs.[40] A systematic literature review that synthesizes intrapersonal and sociocontextual factors of participation in chronic disease self-management programs can result in recommendations for researchers and clinicians to secure high rates of patient enrollment and retention, thus enhancing the rigor of research exploring the effectiveness and quality of chronic disease self-management programs. Therefore, identification of intrapersonal and sociocontextual factors affecting participation in chronic disease self-management is important for improving both enrollment and retention.

To our knowledge, no systematic review has used Andersen's BMHSU as a theoretical framework to explore patient perspectives on the process of enrollment and participation in chronic disease self-management programs. Moreover, no systematic review has evaluated the literature on patient perspectives on factors associated with enrollment and retention in chronic disease self-management programs. To fill this important gap in the literature, the current systematic literature review examined patient perspectives of the predisposing, enabling, and need factors that influence the decision to participate in chronic disease self-management programs. The following three research questions were of primary interest during this review:

1. Which demographic factors, social structures, and health beliefs predispose patients to enroll and participate in chronic disease self-management programs?
2. How do patients perceive social support and community support as enabling factors in their decision to participate in chronic disease self-management intervention programs?
3. What specific health care need(s) do patients and providers report as having an immediate effect on patient participation in chronic disease self-management programs?

## Method

Garrard Matrix Method,[41] a framework used to synthesize health science literature pertaining to a specific research goal or purpose, was used to conduct the systematic review.

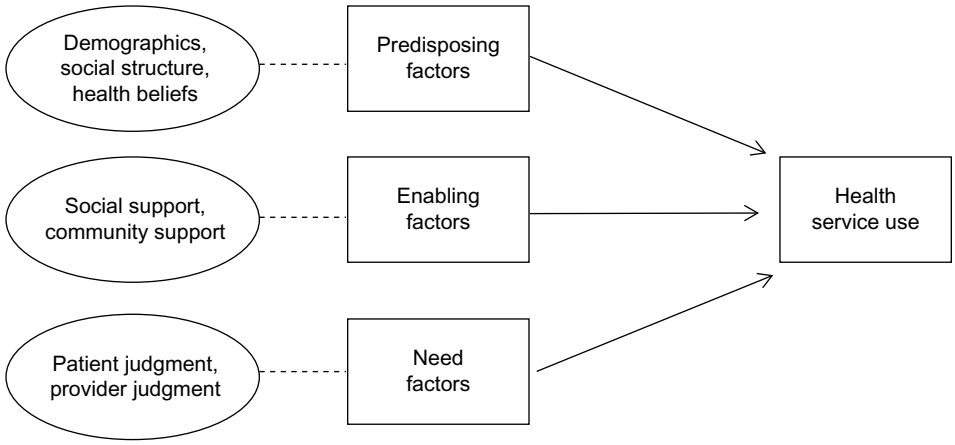


**Figure 1** Andersen's Behavioral Model of Health Services Use.
**Note:** Data taken from Andersen[32,33] and Babitsch et al.[34]

Approximately 2 decades ago, de Boer et al[42] used the BMHSU as a framework to guide a systematic literature review that explored factors predicting hospitalization and use of hospital-based services among individuals diagnosed with a chronic illness.

The following three electronic databases were used to search for and retrieve empirical chronic disease self-management studies published in the English language between 1997 and 2015: PubMed (MEDLINE), CINAHL, and PsycINFO. The following keywords and Boolean operators were entered into the database search engines: ("heart disease" OR "cancer" OR "COPD" OR "type 2 diabetes") AND ("patient perspectives" OR "patient views") AND ("self-management" OR "support") AND ("recruitment" OR "retention"). "Patient perspectives" or "patient views" were defined as attitudes and beliefs about participating in self-management programs possessed by patients living with chronic disease. "Self-management" was defined as a program intended to improve a patient's ability to manage chronic disease symptoms, including physical and psychosocial consequences and lifestyle challenges.[19] Participation in self-management programs was operationalized according to recruitment and retention; where "recruitment" was defined as patients formally choosing to enroll or enter into a chronic disease self-management program, and "retention" was defined as patients actively participating in a chronic disease self-management program until the end of its term.[43]

The following content was extracted from each article meeting the inclusion criteria: 1) study country of origin, 2) chronic disease(s) focused on in the study, 3) chronic disease self-management program description, 4) research design, 5) sample characteristics, 6) attrition rate, and 7) predisposing factors, enabling factors, and need factors associated with patient enrollment and retention in chronic disease self-management programs.

## Study selection

Once all potentially eligible studies were retrieved, one researcher examined the title and abstract of each article to determine whether or not the study met inclusion criteria. Figure 2 is a flowchart depicting the study selection procedure used during the systematic review. Articles were included if they were: 1) primary studies that used qualitative

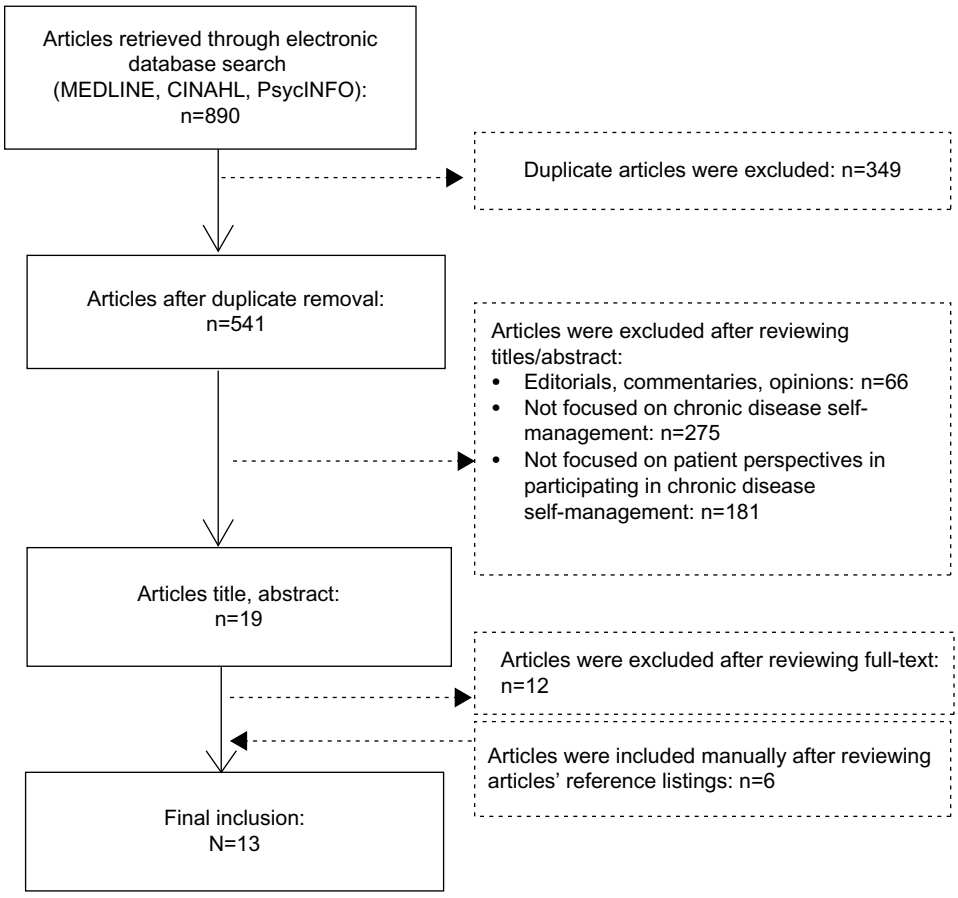


**Figure 2** Flowchart depicting article retrieval, review, and selection processes.

methodology, including semistructured interviews, narrative interviews, focus groups, and open-ended qualitative responses on structured surveys; 2) available in full-text from institutional library resources; 3) focused on self-management programs addressing at least one chronic disease (eg, heart disease, cancer, chronic lower respiratory conditions, type 2 diabetes); and 4) reported patients' attitudes or beliefs regarding decisions to enroll or participate in a chronic disease self-management program. Articles were excluded if they were: 1) editorials, commentaries, or opinion pieces (n=66); 2) not an investigation of chronic disease self-management (n=275); or 3) not directly reporting qualitative accounts of patients' attitudes and beliefs that are related to their enrollment and participation in a chronic disease self-management program (n=181). Articles available in full-text were excluded if qualitative patient feedback or perspectives about enrolling and participating in chronic disease self-management programs were not reported (n=12). The reference listing of each remaining article was then perused to identify additional studies that met inclusion criteria (n=6).

To ensure reliability of the article selection process, a second member of the research team independently reviewed the title and abstract of each retrieved article to determine whether or not the article met inclusion criteria. In the case that the reviewers could not reach consensus, a third member of the research team was available to resolve any discrepancies. Disagreements regarding one questionable article were discussed, leading to the removal of the article from the final list.

## Measures

A code sheet was developed based on operationalized definitions of predisposing, enabling, and need factors described in the BMHSU. Table 1 presents the operational definitions

**Table 1** Operational definitions of Andersen's BMHSU factors adapted for participation in chronic disease self-management programs

| BMHSU factors | Operational definition of individual factors |
|---|---|
| **Predisposing factors** | |
| Demographics | |
| Age | Patient discusses how their age (in years) has implications for participation. |
| Sex | Patient identifies how sex serves a role in their decision to participate. |
| Marital status | Patient discusses the implications of being single, divorced, widowed, or separated on participation. |
| Race/ethnicity | Patient discusses how their racial and/or cultural identity impacts participation. |
| Social structure | |
| Income | Patient identifies how financial status influences their participation. |
| Education | Patient identifies how their education level (eg, high school, college, GED) impacts participation. |
| Occupation | Patient discusses how their job influences participation. |
| Location | Patient discusses that their geographical residence (rural, urban, suburban) impacts participation. |
| Health beliefs | |
| Knowledge | Patient discusses how/what they know about their disease and/or its self-management, and how this affects program participation. |
| Attitude | Patient expresses favorable or unfavorable evaluations of participating in self-management programs. |
| Cultural norms | Patients discuss how their cultural values and beliefs influence program participation. |
| **Enabling factors** | |
| Social support | |
| Family assistance | Patient identifies that their health care support is dependent on family member(s) assistance. |
| Health insurance | Patient identifies how health insurance enrollment (or lack thereof) influences participation. |
| Social/emotional support | Patient discusses the implications of having (or not having) social or emotional support from family and/or friends, and how the support level has implications on their participation. |
| Conflicts | Patient discusses the implications of other health care appointments or prior engagements in facilitating or hindering their participation. |
| Community support | |
| Regular health care source | Patient implies that their usual/regular health care source (eg, nurse practitioner, family doctor) influences their participation. |
| Access to health source | Patient discusses the distance to/from self-management programs, and the availability and accessibility of self-management programs. |
| Affordability of programs | Patients discuss the implications of the financial cost as a facilitator or barrier to participation. |
| **Need factors** | |
| Patient judgment | Patient discusses the perceived severity of and susceptibility to their condition, the perceived susceptibility of the condition to worsen, and health-related quality of life implications for participation. |
| Provider judgment | Patient discusses how their health care provider (eg, nurse practitioner, physician) judges their health status and its implications for participation. |

**Abbreviations:** BMHSU, Behavioral Model of Health Services Use; GED, general educational development.

**Table 2** Characteristics of studies included in the review (N=13)

| Source | Country of origin | Chronic disease | Qualitative method | Study purpose | Attrition rate | Sample size | Available demographics |
|---|---|---|---|---|---|---|---|
| Hallberg et al[52] | Sweden | Cardiovascular disease | Semistructured interviews | Aimed to understand patient perspectives of participating in phone-based systems to support self-management behaviors. | Not reported | n=49 | 37–81 years old; 53%, male; 51.2%, at least a high school education; 77.5%, married |
| Wermeling et al[53] | Germany | Diabetes | Narrative interviews | Explored patient perceptions of participating in diet counseling and engaging in self-management behaviors over time | Not reported | n=35 | 59 years (min =35; max =77), average age; 54%, male |
| Coventry et al[45] | United Kingdom | Cardiovascular disease, chronic lower respiratory disease, type 2 diabetes, osteoarthritis, depression | Semistructured interviews | Explored patient and provider's perspectives on factors that facilitate or hinder patient participation in chronic disease self-management programs | Not reported | n=20 | 62.4 (min =52; max =88), average age |
| Jolles et al[54] | Canada | Cardiovascular disease | Semistructured interviews | Explored barriers and facilitators to patient participation in hypertension self-management | Not reported | n=26 | 57 years (SD =16), average age; 48%, male |
| Flynn et al[47] | United States of America | Cardiovascular disease | Focus groups | Explored barriers and facilitators of patient participation in hypertension self-management among urban African Americans | Not reported | n=18 | 30–82 years old; 33.3%, male; 93%, at least a high school education |
| Jackson et al[44] | United Kingdom | Cardiovascular disease | Narrative interviews | Explore why patients do not use cardiac rehabilitation or heart disease self-help groups | Not reported | n=27 | 40–89 years old; 62.9%, male |
| Rankin et al[49] | United Kingdom | Diabetes | Semistructured interviews | The purpose of the study was to explore patient perceptions of experience in DAFNE, which is a structured educational program adapted from the Diabetes Treatment and Teaching Program | Not reported | n=30 | 36.1 years (SD =11.6), average age; 46.7%, male |
| Sohanpal et al[50] | United Kingdom | Chronic lower respiratory disease | Semistructured interviews | Explore why patients with COPD participate in the BELLA program, which addresses skills (ie, define the problem, decision-making, resource accessibility, social networks) to enhance patient self-efficacy for self-management | n=26 participants were recruited for the interview; n=16 completed the interviews (ie, 9 "high attenders" and 7 "poor attenders") | n=16 | 69.5 years (min =49; max =89), average age; 43.75%, male |
| Willis et al[46] | Australia | Chronic lower respiratory disease | Semistructured interviews | Explore chronic disease patients' motivation to participate in the CDSM program, which includes group learning through peer leaders trained to motivate and empower patients to self-manage their condition and symptoms | Not reported | n=19 | 40–70 years old; 31.6%, male |
| Gucciardi et al[37] | Canada | Type 2 diabetes | Mixed method: (semistructured interviews) | The program was hosted at a Diabetes Education Center where patients received one-on-one health assessments with a dietitian and nurse to develop a tailored action plan to self-manage symptoms<br>The study explored factors that contribute to participants' (n=118) attrition | n=267 participants were enrolled; n=149 (55.8%) completed the program; n=118 enrolled but prematurely withdrew from the study | n=118 | 56.80 years (SD =11.8), average age; 50.8%, male; 46.7%, at least a high school education; 68.1%, married |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Lavery et al[51] | United Kingdom | Chronic lower respiratory disease | Focus groups | The study explored obstacles and sources of support in the self-management of bronchiectasis | Not reported | n=32 | 18+ years old; 44%, male |
| Bower et al[55] | United Kingdom | Arthritis, asthma, type 2 diabetes, depression, heart disease, others | Narrative interview | REPORT, similar to CDSM, explores cost-effectiveness, self-management, and health-related outcomes<br>The study aimed to explore chronic disease patients' preferences and motivations for recruitment and retention in REPORT | Not reported | n=28 | 49 years, average age (min =25; max =75); 32%, male |
| Carlsson et al[48] | Sweden | Gynecologic, breast, and prostate cancers | Mixed method (open-ended items on a structured survey) | The study explored cancer patients' perspectives on factors that motivate recruitment and retention in cancer management and patient recovery associations, which provide patients with support and information about their cancer and its self-management | n=1,800 were recruited; n=1,576 (87%) enrolled; n=1,400 (88.8%) completed the study | n=1,400 | 64 years, average age (min =23; max =91); 42%, male |

**Abbreviations:** DAFNE, dose adjustment for normal eating; BELLA, better living with long term airways; CDSM, chronic disease self-management; REPORT, research into expert patients outcomes in a randomised trial; SD, standard deviation; COPD, chronic obstructive pulmonary disease.

for each intrapersonal and sociocontextual factor identified in Andersen's BMHSU.[32–34,37]

## Data analysis

A descriptive analysis of qualitative data from patients on enrollment and retention was conducted for each reviewed study. Study characteristics (eg, study of origin, chronic disease type, research design/method, program description/study purpose, sample size, and attrition rate) were compiled and are summarized in Table 2. Summaries of qualitative data describing BMHSU factors were extracted from each article and are summarized in Table 3.

# Results

## Characteristics of reviewed studies

Thirteen (N=13) studies from six different countries (United Kingdom, Germany, Sweden, Canada, United States, Australia) met the inclusion criteria for this review. Studies were conducted in the United Kingdom (n=6; 46.15%), Sweden (n=2; 15.38%), Germany (n=1; 7.69%), Canada (n=2; 15.38%), Australia (n=1; 7.69%), and the United States (n=1; 7.69%). Reviewed studies primarily focused on self-management of cardiovascular disease (n=4; 30.77%), chronic lower respiratory diseases (n=3; 23.08%), and diabetes (n=2; 15.38%). Two (15.38%) studies focused on self-managing several chronic diseases (eg, arthritis, type 2 diabetes, chronic obstructive pulmonary disease [COPD], mental health, cancers) concurrently, and a final study (n=1; 7.69%) reported on gynecologic, breast, and prostate cancers. Table 3 provides descriptive summaries of how each reviewed study included Andersen's BMHSU factors and whether or not the factors influenced patient enrollment and/or retention in self-management. The following sections provide a synthesis of descriptive summaries from each factor.

## Predisposing factors

### Demographic and social structure

Few studies presented results identifying demographic or social structure factors that influence chronic disease patients' enrollment and participation in self-management programs; however, in two studies, older age,[44] low income,[44,45] and one's commitment to their job[44] were identified as factors negatively affecting patients' enrollment and continued participation in self-management programs.

### Health beliefs

Disease-related knowledge, attitudes, cultural norms, and current comorbidities were identified as factors affecting the

**Table 3** Studies included in the review (N=13) of BMHSU factors impacting participation in chronic disease self-management programs

| Chronic disease | Source | BMHSU factor | Description of each BMHSU factor | Factor affecting enrollment, retention, or both |
|---|---|---|---|---|
| Cardiovascular disease | Flynn et al[47] | Predisposing factors | Limited knowledge about hypertension delayed the onset of participation in self-management programs. | Enrollment |
| | | | Presence of comorbidities reduced patients' motivation to participate in hypertension self-management programs. | Enrollment/retention |
| | | Enabling factors | Patients with strong family support networks reported greater participation in self-management programs. | Enrollment/retention |
| | | | Patients identified God as a source of support in self-managing symptoms. | Enrollment/retention |
| | | | Patients reported trusting the current care from health care provider, but identified long appointment waiting times as a barrier to carrying out self-management. | Enrollment/retention |
| | | | Free health-related events (eg, blood pressure screenings, skill building seminars) sponsored by community organizations increased patients' motivation to participate in self-management programs. | Enrollment |
| | | Need factors | Increased severity of hypertension and associated health-related outcomes increased patients' perceived need to participate in self-management programs. | Enrollment/retention |
| Cardiovascular disease | Hallberg et al[52] | Predisposing factors | Opportunity to increase knowledge about hypertension increased patients' interest to participate in self-management programs. | Enrollment |
| | | Enabling factors | Self-reporting self-management behaviors served as a means of social support to sustain the behavior. | Retention |
| | | | Opportunity for follow-up and feedback from program facilitator(s) increased patients' motivation to participate in self-management programs. | Enrollment/retention |
| | | Need factors | Patients who had stabilized blood pressure or perceived their symptoms as less severe did not feel the self-management program was relevant to them. | Enrollment/retention |
| Cardiovascular disease | Jackson et al[44] | Predisposing factors | Older age was perceived as a limitation that prevented patients from participating in cardiovascular disease self-management. | Enrollment |
| | | | Limited financial and transportation resources inhibited patients from participating in self-management programs. | Enrollment |
| | | | Work schedules inhibited patients from participating in self-management programs. | Enrollment/retention |
| | | | Limited knowledge influenced patients' abilities to make informed decisions about participating in self-management programs. | Enrollment |
| | | | Complex instructions prevented patients from participating in self-management programs. | Retention |
| | | | Negative perceptions about group self-management programs inhibited patients' participation. | Enrollment |
| | | | Perception that only a medical or surgical intervention could promote better health (not self-management). | Enrollment |
| | | | Presence of comorbidities negatively influenced patients' physical ability to attend and participate in self-management programs in a social or group setting. | Enrollment/retention |
| | | Enabling factors | Minimal social support from family and friends increased patients' motivation to participate in self-management programs where they could share experiences with peers and health care providers. | Enrollment |
| | | | Difficulty understanding how an additional self-management program would benefit patients beyond the treatment from health care providers inhibited patients' participation in self-management programs. | Enrollment |
| | | Need factors | N/A | N/A |

(*Continued*)

**Table 3** (*Continued*)

| Chronic disease | Source | BMHSU factor | Description of each BMHSU factor | Factor affecting enrollment, retention, or both |
|---|---|---|---|---|
| Cardiovascular disease | Jolles et al[54] | Predisposing factors | Patients received education from health care providers, but received additional education from pharmacists and specialists. | Enrollment/retention |
| | | Enabling factors | Limited support from family members reduced patients' motivation to participate in hypertension self-management behaviors (eg, physical activity). | Enrollment |
| | | | Conflicts between patients' schedules/routines and hypertension self-management inhibited participation. | Enrollment/retention |
| | | Need factors | Motivation to participate in self-management programs increased only when patients experienced exacerbated symptoms (eg, headache, dizzy). | Enrollment |
| | | | Presence of family history and fear of worsening symptoms increased patients' motivation to participate in hypertension self-management programs. | Enrollment |
| Chronic lower respiratory disease | Lavery et al[51] | Predisposing factors | Limited knowledge about lower respiratory disease and its self-management lowered patient motivation to participate. | Enrollment |
| | | | Conflicts between patients' schedules/routines (eg, holidays, minimal time in schedules) inhibited participation. | Enrollment/retention |
| | | Enabling factors | Family support influenced patients' self-management. | Enrollment/retention |
| | | Need factors | Absence of pain or discomfort decreased patients' motivation to participate in self-management programs. | Enrollment/retention |
| | | | Presence of disease severity negatively influenced the ability of patients to participate in self-management programs. | |
| Chronic lower respiratory disease | Sohanpal et al[50] | Predisposing factors | Patients were interested in participating in self-management programs to learn more about the condition and help others living with COPD. | Enrollment/retention |
| | | | Negative perceptions about self-management limited comfort with other participants. | Enrollment/retention |
| | | | Negative perceptions of lengthy and time consuming self-management programs reduced interest in participation. | Enrollment/retention |
| | | Enabling factors | Opportunity to socialize was one of the greatest motivating factors for participating in COPD self-management. | Enrollment/retention |
| | | | Limited family or social support for patients inhibited patient participation in self-management programs. | Enrollment/retention |
| | | Need factors | Perception that COPD was not negatively affecting the health-related quality of life or lifestyle of patients inhibited self-management participation (even among those diagnosed with moderate-to-severe COPD). | Enrollment/retention |
| Chronic lower respiratory disease | Willis et al[46] | Predisposing factors | Limited knowledge and understanding about the value of COPD self-management program above and beyond standard of care from health care providers reduced patient interest to participate. | Enrollment/retention |
| | | | Continuous follow-up and progress checks with providers and program facilitator(s) enhanced patients' interest to participate. | Enrollment/retention |
| | | | Perception of altruism and helping others living with COPD motivated patients to participate in self-management programs. | Enrollment/retention |
| | | | Presence of comorbidities enhanced patients' interest in participating in COPD self-management programs, because patients could have a better overall sense of their holistic health and self-management needs. | Enrollment/retention |
| | | Enabling factors | Opportunity for social support with peers, health professionals, and mentors motivated patients to participate in COPD self-management. | Enrollment/retention |
| | | Need factors | N/A. | N/A |

(*Continued*)

**Table 3** (*Continued*)

| Chronic disease | Source | BMHSU factor | Description of each BMHSU factor | Factor affecting enrollment, retention, or both |
|---|---|---|---|---|
| Diabetes | Wermeling et al[53] | Predisposing factors | Limited knowledge or skills about type 2 diabetes self-management reduced patients' interest to participate in self-management programs. | Enrollment |
| | | | Perception that type 2 diabetes self-management cannot be easily integrated into daily lifestyles reduced patients' interest to participate. | Enrollment |
| | | | Perception that type 2 diabetes self-management programs do not take into account patients' cultural preferences (eg, diet) reduced interest to participate. | Enrollment/retention |
| | | Enabling factors | Health care provider referral of patients to type 2 diabetes self-management resources decreased patients' motivation to participate in self-management programs. | Enrollment |
| | | Need factors | Absence of pain or discomfort attributed to type 2 diabetes decreased patients' motivation to want to participate in self-management programs. | Enrollment |
| Diabetes | Rankin et al[49] | Predisposing factors | Limited knowledge or confidence in the ability to independently interpret blood glucose readings reduced motivation to participate. | Retention |
| | | | Opportunity for follow-up and feedback from program facilitator(s) increased patients' motivation and interest to participate. | Enrollment/retention |
| | | | Negative perceptions existed on group self-management and reduced interest in participation (one-on-one and individualized treatment was most desired). | Enrollment/retention |
| | | | Negative perceptions that programs did not address existing comorbidities, which reduced patients' motivation and interest to participate in disease-specific self-management programs. | Enrollment/retention |
| | | Enabling factors | Opportunity for social support and alleviating social isolation motivated patients to participate in self-management programs. | Enrollment/retention |
| | | | Conflicts between patients' schedules/routines (eg, work schedule) inhibited participation. | Enrollment/retention |
| | | Need factors | N/A. | N/A |
| Diabetes | Gucciardi et al[37] | Predisposing factors | Limited knowledge about self-management programs decreased patients' motivation to participate in type 2 diabetes self-management programs. | Retention |
| | | | Increased self-efficacy to independently learn type 2 diabetes self-care behaviors reduced patients' interest to participate in self-management programs. | Retention |
| | | | Conflicts between patients' schedules/routines inhibited participation. | Retention |
| | | | Existence of comorbidities made participation in type 2 diabetes self-management programs very challenging. | Retention |
| | | Enabling factors | Limited support from family and friends inhibited patient participation in type 2 diabetes self-management programs. | Retention |
| | | | Satisfaction with self-management care provided by health care providers decreased patients' interest to participate in an additional type 2 diabetes self-management program. | Retention |
| | | Need factors | Limited perceived severity of type 2 diabetes reduced patients' motivation to participate in self-management programs. | Retention |
| | | | Health care providers deemed patients' type 2 diabetes as moderate or not severe, which reduced patients' motivation or immediate need to participate in self-management programs. | Retention |
| Multiple chronic conditions | Coventry et al[45] | Predisposing factors | Limited financial and transportation resources contributed to lack of participation in chronic disease self-management programs. | Enrollment/retention |
| | | | Presence of comorbidities reduced patients' motivation to participate in self-management programs. | Enrollment/retention |
| | | Enabling factors | Support from family, friends, and community/religious organizations increased patients' motivation to participate in self-management programs. | Enrollment/retention |
| | | | Satisfaction with care provided by primary care providers decreased patients' motivation to participate in an additional self-management program. | Enrollment/retention |
| | | Need factors | N/A. | N/A |

(*Continued*)

**Table 3** (*Continued*)

| Chronic disease | Source | BMHSU factor | Description of each BMHSU factor | Factor affecting enrollment, retention, or both |
|---|---|---|---|---|
| Multiple chronic conditions | Bower et al[55] | Predisposing factors | Perception of altruism and helping others living with COPD motivated patients to participate in self-management programs. | Enrollment |
| | | Enabling factors | N/A. | N/A |
| | | Need factors | N/A. | N/A |
| Cancer (gynecological, breast, prostate) | Carlsson et al[48] | Predisposing factors | Opportunity to increase knowledge about cancer (gynecological, breast, and prostate) self-management and treatment motivated patients to participate in self-management programs. | Enrollment |
| | | Enabling factors | Opportunity for social interaction with others living with gynecological, breast, and prostate cancers increased motivation to participate in self-management programs. | Enrollment |
| | | Need factors | N/A. | N/A |

**Abbreviations:** BMHSU, Behavioral Model of Health Services Use; COPD, chronic obstructive pulmonary disease; N/A, not applicable.

health beliefs of patients. Each of these factors differentially influenced patient participation in chronic disease self-management programs.

## Knowledge

Limited disease-related knowledge was identified as a prevalent factor that negatively influenced patient enrollment and participation in chronic disease self-management. For example, patients living with chronic lower respiratory conditions reported limited knowledge about the purpose of self-management programs, the potential benefits derived from such programs, low expectations for each program session, and unclear goals that could be achieved through participation.[46] Patients in other studies reported that limited knowledge about self-management programs and how to carry out recommended self-care behaviors made it difficult to make an informed decision about participating in a self-management program,[37,44,46] which led to delayed enrollment in some studies[44,47] and eventual drop-out in another.[37]

Enrollment in self-management interventions was also negatively influenced by patients' limited knowledge about the pathophysiology of their disease, possible benefits of participating in self-management, and understanding the best self-management behaviors for improving symptom management.[37,44,46–53] Additionally, patients were less likely to enroll and participate in self-management programs if the content and instructional methods were perceived as too complex or difficult to understand. Interestingly, patients living with cancer reported accessing patient education resources available both online and offline about their condition.[48] Lack of patient understanding of program guidelines led to low self-efficacy, frustration, and self-doubt to engage in the health promoting behaviors in two reviewed studies.[44,49]

## Attitudes

Both positive and negative attitudes toward enrollment and retention in self-management programs existed among patients participating in the reviewed studies. Patients also reported unfavorable attitudes toward enrolling and participating in guided self-management programs due to already high preexisting knowledge of how to best self-manage their own chronic condition.[37,54] However, in two studies, patients living with COPD and hypertension reported several positive attitudes toward participating in self-management programs, including the opportunity to learn more about their condition.[50,52] Patients living with various chronic diseases, including cardiovascular disease, chronic lower respiratory conditions, and type 2 diabetes, reported not enrolling, because self-management programs would not teach them anything new and different from what they already learned from their general practitioner.[44,45] Some patients specifically believed that they would not benefit from self-management in any meaningful way as compared to medical or surgical intervention.[44]

Patients with type 2 diabetes in one study did not identify self-management as a priority for their health and general lifestyle.[37] Patients with chronic lower respiratory conditions also reported negative attitudes toward participating in self-management programs where sessions last over 3 hours.[50] This finding was similar to what was found among patients living with cardiovascular disease[44] and type 2 diabetes,[53] who reported that self-management instructions are too complex and time consuming, making the recommendations too difficult to understand and integrate into their everyday lifestyles. Finally, patients living with chronic disease (ie, chronic lower respiratory conditions, diabetes, heart disease) in three studies reported negative attitudes toward group self-management programs, because they did not know or were

not comfortable around other patients due to concerns about the potential of violating patient confidentiality.[44,49,50]

### Cultural norms

Patients in several studies reported that the decision to enroll and participate in chronic disease self-management programs was due to altruistic and cultural/religious values. Patients believed that it was their duty or calling to participate in self-management programs and research, because they would be helping themselves and those currently or eventually suffering with the condition.[46,50,55] Also, patients living with type 2 diabetes[53] stated that they were not likely to participate in self-management programs, because learning modules did not take into account the value that patients place on the social and cultural aspects of cooking, the pleasure of eating tasty foods, and the relationship between food and one's identity.

### Comorbidities

Patients in several studies reported that comorbidities negatively affected their decision to enroll in chronic disease self-management programs.[37,45,47] These patients stated that self-management programs for one specific chronic disease would not benefit them, because additional comorbidities were present and not addressed in programs focused on managing only one condition.[44] Other patients believed that living with multiple chronic diseases and participating in a self-management program would result in confusion about recommended self-care behaviors, including medication regimens prescribed by health care providers for various conditions.[47,49] Another study reported contradictory findings, noting that patients with chronic lower respiratory conditions and comorbidities participated in self-management programs, because these programs allowed them to have a better sense of their health status and self-management needs.[46]

## Enabling factors

### Social support

Patients in several studies identified social support as a significant factor impacting their decision to enroll and continue participating in chronic disease self-management programs.[46,49,50] Strong social support from health care providers and self-management program facilitators predicted patients' interest in enrollment and continuous participation.[46] In one study among African–American adults with hypertension, God was identified as a significant source of support in their self-management participation.[47] However, patients reported that enrollment and participation in chronic disease self-management behaviors was complicated by their dependence on family members,[44,50,51] especially those who required informal care and assistance.[45,47,54] Although patients reported that social and emotional support from family and friends was important in facilitating their self-management behaviors,[51] participants also reported poor family support as precluding self-management.[37,44] Some patients believed that asking for assistance with self-management would become a burden on their family and friends.[48]

Patients generally reported receiving chronic disease self-management support from their health care provider or pharmacist.[37,44,47] While some health care providers referred patients to organized group self-management programs,[53] others did not refer patients for reasons that were unknown and undisclosed.[44,51] Some patients living with type 2 diabetes reported they simply did not want to enroll or participate in a self-management program that fell outside of the care and support provided by their primary care provider.[37] Patients with cardiovascular disease, who reported trusting the self-management care by their health care provider, suggested that frequent calls about appointment and medication reminders kept them on track with their self-management, but extended wait periods to see their health care provider served as a significant barrier to carrying out self-management behaviors.[47]

### Community

Transportation was also a significant barrier associated with poor patient participation in chronic disease self-management.[44,45,50] However, some patients simply did not want to be away from their home to participate in self-management programs for an extended period of time, even if transportation subsidies or services were available.[50]

### Personal conflicts

Conflicts arising in patients' personal lives were also identified as influential factors negatively affecting enrollment and participation in chronic disease self-management programs. Patients reported that they would not participate or would eventually drop out of a program if it interfered with personal issues such as employment, hobbies, social life, and family vacations.[37,49–51,54]

## Need factors

Most often, participants did not enroll in self-management programs because they perceived their disease status to be of minimal severity and they did not feel susceptible to potential disease-related complications.[37,50] However, in two

studies, perceived severity of disease and family history of hypertension were associated with greater motivation and perceived need to participate in self-management programs.[47,54] Two other studies indicated that patients without debilitating symptoms who did not require immediate medical attention were less likely to participate in self-management behaviors and programs.[51,53]

## Discussion

This review synthesized qualitative research to understand patient attitudes and beliefs on the intrapersonal and sociocontextual factors that influence the decision to enroll and participate in self-management programs. This systematic review used Andersen's BMHSU framework to explore patient perspectives of predisposing, enabling, and need factors that facilitate or hinder patient enrollment and retention in chronic disease self-management. The findings of this review identified several predisposing and enabling factors reported by patients as influencing their enrollment and retention in chronic disease self-management. Although need factors were represented across the reviewed studies, patients rarely discussed their health care provider's perception about their need to participate in self-management; rather, the need to participate in self-management was most often presented according to the patient's own judgment.

### Predisposing factors

Limited knowledge about chronic disease negatively influenced the ability of patients to make informed decisions about whether or not to enroll and participate in a self-management program. It is not uncommon for patients with chronic disease to have limited knowledge and understanding about how to self-manage their symptoms for better health-related outcomes and an enhanced quality of life.[56,57] Research suggests that sufficient knowledge about disease-specific risk factors, disease diagnostics and treatment, and the importance of self-managing symptoms to prevent detrimental health outcomes are important for patients to make an informed decision about whether or not to participate in chronic disease self-management.[32,37,58–60] Findings from this review suggest that patient enrollment and retention was negatively influenced among those patients who did not fully understand the pathophysiology of their condition, the impact that their condition will have on their health-related quality of life, and how to coordinate chronic disease care and treatment, especially when living with comorbidities.

Chronic disease self-management programs that are easy to use and not burdened with complex, technical instructions were reported as most appealing to patients in the current review. Patients with chronic disease typically have low health literacy skills,[7] which is defined as insufficient skills to effectively locate, appraise, and act upon health-related information.[61] Limited health literacy contributes to poor disease-related knowledge, low perceived disease self-management skills, poor quality of life indicators, and detrimental health outcomes, including premature mortality.[7,25,62] The impact of low health literacy on self-management program enrollment and retention has yet to be fully explored, especially among patients living with chronic lower respiratory conditions.[62] However, the use of health literacy strategies to increase patient access to understandable and actionable self-management information has been shown to increase disease-specific knowledge[62] and activate patient health care decision-making.[63]

Negative attitudes toward chronic disease self-management programs were associated with little interest in enrollment. Patients in several reviewed studies believed that chronic disease self-management programs would not provide additional benefits beyond the care and instruction from their primary health care provider. Health care providers are considered to be their most trustworthy source of health information.[64] Also, research suggests that patients are more willing and more likely to enroll in a chronic disease self-management program if a general practitioner or nurse endorses the program.[31,65] Therefore, health care providers and clinicians play a critical role in enrolling and retaining patients into self-management programs. Despite this research, health care providers rarely refer their patients to participate in health care research and rarely discuss the process and implications of enrolling, which include potential participation in ongoing clinical trials.[66] Researchers who are interested in recruiting chronic disease patients to participate in self-management programs and interventions should develop collaborative, working relationships with health care providers to assist with enrolling patients for the recommended programs. Developing these collaborative relationships can assist health care providers to translate and communicate the importance, benefits, and process of enrolling and participating in chronic disease self-management programs to patients in a way that is understandable, actionable, and sustainable.

### Enabling factors

Patients in the reviewed studies reported receiving little social and emotional support from family members or friends with regard to chronic disease self-management. The primary motivator for patients choosing to enroll in

self-management programs in this review was to receive support from health care providers, facilitators, and peers who they could relate to and learn from. Chronic disease self-management should be patient-centered, where instruction is tailored and goal-oriented with customized feedback and follow-up from program facilitators who can devote more time than health care providers to support and provide recommended standards for quality chronic disease self-care.[62,67,68] Positive associations exist between perceived social support and participation in chronic disease self-management, even among culturally diverse populations with a variety of chronic disease diagnoses.[16,18,19] However, the mechanism by which social support enhances chronic disease self-management and associated outcomes is less understood.[17] Social support is broadly defined, but includes both social integration (ie, reciprocal communication) and functional support (eg, instrumental, emotional support).[69]Although patient preferences for the type and amount of social support vary according to their individual circumstance,[69] research suggests there is a need to explore which types of social support are most effective for chronic disease self-management and if the type of effective support mechanisms vary by the chronic disease and specific self-management behaviors.[17]

Patients reported that the duration and time of day or week that self-management programs are offered is an important enabling factor affecting enrollment and retention. Patients in the reviewed studies reported that it was not possible to engage in recommended self-management behaviors for more than 3 hours at a time or every day of the week due to schedule conflicts. This finding is consistent with recent research suggesting that low enrollment and retention in self-management programs may be due to a patient's inability to incorporate program sessions and recommended behaviors into their daily routine.[70] However, with the rising adoption of community-based participatory research and advancements in technology, chronic disease self-management programs are now widely available through community centers and on the Internet, where patients can experience flexible and continuous interaction with program facilitators, peers, and health care providers.[27]

Patients in the reviewed studies reported avoiding or withdrawing from in-person group self-management programs, partially because they were concerned about their privacy and confidentiality. For example, patients reported losing interest or not feeling comfortable participating in a group setting self-management program if they did not know other patients on a personal level. Confidentiality in health care service delivery has been identified as a significant barrier to the use of both in-person and eHealth services and programs.[32,33]

Internet-based and eHealth technologies allow patients the opportunity to access patient education resources and communicate with peers and providers at a time that is convenient for them and their schedule, rather than attending an in-person session with an established date and time. However, there is limited evidence-based research that has evaluated the feasibility or effectiveness of eHealth technologies.[71] Few published studies have reported patient preferences or perspectives on why and how they would use eHealth to participate in chronic disease self-management.[9,72] In one study, the usability, feasibility, and acceptability of emerging health technologies in chronic disease self-management was reported as generally high among both patients and providers;[9] however, robust research with adequate sample sizes must be conducted to determine the effectiveness, quality and cost-effectiveness of eHealth self-management services.

## Need factors

Among those studies reporting need factors, patients only discussed their personal judgment and perception about the need to participate in self-management. Patients who reported little interest or motivation to participate in chronic disease self-management programs believed their disease was not severe enough to justify participation and consequently reported not feeling susceptible to negative health-related outcomes. Low perceived severity and susceptibility to symptoms caused by a condition, otherwise known as perceived threat, is associated with both delayed self-management and poor self-management program adherence.[73] Need factors, which are the most immediate causal factors of enrollment and use of health programs, are comprised of both patient and provider perceptions of a patient's health status.[32,33] Findings of the current review suggest that patients may not consider or be aware of their provider's judgment about participating in chronic disease self-management programs, which may be caused by unsatisfactory patient/provider communication.[74]

A defining feature of patient-centered care, which has been shown to have positive effects on health-related outcomes and patient satisfaction,[75] is effective patient/provider communication where patients and providers work alongside one another as allies in coordinating health care.[76] In patient-centered communication, health care providers facilitate shared decision-making by explaining health care/treatment options with patients, actively eliciting patient perspectives about health care options, understanding patients' unique

personal and cultural attributes, and ensuring that health decisions are shared and effective.[75] If patients are not well informed about their condition, health care options, and their provider's judgment of their current health status, then they may have a difficult time engaging in the shared decision-making process and may have limited confidence to process and appraise information to make an informed health decision about participating in self-management. Health care providers and researchers should use health literate and patient-centered approaches to recruit and enroll patients in chronic disease self-management interventions,[67] and specifically use strategies that consider relevant beliefs and attitudes, such as perceived threat associated with their chronic disease(s). Future research should explore how providers discuss implications of participating in self-management programs with chronic disease patients, and why providers do or do not endorse health care research for self-management to their patients.

## Strengths and limitations

This systematic review was conducted with a widely used systematic review framework, Garrard's Matrix Method. Moreover, Andersen's BMHSU was used as a framework to guide the synthesis of patient perspectives about the intrapersonal and sociocontextual factors influencing their enrollment and retention in self-management. A variety of chronic diseases were represented in the current review, including cardiovascular disease (ie, hypertension, cardiac disease), diabetes (ie, type 1 and type 2), and chronic lower respiratory conditions (ie, COPD, bronchiectasis). Although a sound systematic approach was used to search for empirical studies that met inclusion criteria, the final sample of studies was somewhat limited (N=13). Also, this review did not evaluate the quality or methods used to verify the validity of qualitative research methods applied in each study, including triangulation and respondent validation.[77]

# Conclusion

This systematic review used Andersen's BMHSU to synthesize results from 13 empirical qualitative studies exploring predisposing, enabling, and need factors that affect patients decision to enroll and participate in chronic disease self-management. Findings of the review suggest that predisposing (eg, low disease-specific knowledge), enabling (eg, insufficient social support, scheduling conflicts), and need (eg, low perceived severity of disease) factors can influence the decision to enroll and participate in chronic disease self-management. Health care providers can begin securing patient enrollment and retention in chronic disease self-management through effective patient/provider communication, which can be achieved by practicing patient-centered communication and collaborating with researchers to translate information that reinforces patient understanding of chronic disease(s), the health threat(s) they face due to their condition, and the health-related and social benefits of participating in self-management. Future research should explore intrapersonal and sociocontextual factors in using eHealth technologies for chronic disease self-management services, where patients can anonymously receive social support, real-time follow-up from providers or group facilitators, and patient education resources that do not conflict with personal or work commitments.

# Disclosure

The authors report no conflicts of interest in this work.

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