



## Self-management interventions for adults with chronic diseases who have limited health literacy in high, middle, and low-income countries: A scoping review

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### Abstract

### Review Article

**BACKGROUND:** Tailored self-management interventions to address the disparities in health outcomes faced by patients with chronic diseases and limited health literacy (HL) are critical. Therefore, an appropriate self-management intervention framework is needed to guide the development and implementation of interventions. The purpose of this review was to summarize the self-management interventions available in high, middle, and low-income countries for adults with chronic diseases who possibly had limited HL.

**METHODS:** This scoping review searched 13 electronic databases (PubMed, Academic Search Ultimate, Africa-Wide Information, APA PsycArticles, APA PsycInfo, CINAHL with Full Text, Communication & Mass Media Complete, ERIC, Health Source: Consumer Edition, Health Source: Nursing/Academic Edition, Humanities Source Ultimate, MEDLINE, Sociology Source Ultimate) without language or time restriction. A piloted data-charting form was used, and the charted data were analyzed according to population, concept, and context (PCC) frequency counts. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist was used as a reporting guide.

**RESULTS:** A total of 13 studies with 3522 participants met the inclusion criteria. The majority of studies had been conducted in high-income countries, using either randomized controlled trials (RCTs) or quasi-experimental designs. The most common types of chronic diseases in the studies were diabetes and chronic pulmonary disease/asthma. Four main types of self-management interventions were identified, and the types varied by administration settings. Underpinning frameworks, timeframes, presenters, outcomes, and recommendations were found to vary across the types of interventions.

**CONCLUSION:** No specific evidence of self-management interventions for adults with chronic diseases and possibly limited HL was found in low and middle-income countries by this review. Evidence from high-income countries refers to four main types of interventions that should be considered when developing interventions targeting similar population groups. Further primary research in low and middle-income countries is recommended.

**KEYWORD:** Chronic Diseases; Health Literacy; Self-Care; Self-Management

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### Introduction

Despite increasing recognition of the

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importance of a chronic disease self-management model for reducing the burden of medical costs and improving patient health outcomes, the burden of medical costs and poor health outcomes still exists for some patients.<sup>1-3</sup> The global burden of chronic



diseases is increasing, and the traditional medical model of caring for patients with chronic disease, which focuses more on the disease than the patient as a whole, is expensive and often ineffective.<sup>4,5</sup> A model for chronic disease self-management has emerged as a supplement to the existing traditional medical model, and has attracted the interest of researchers, health professionals, and patients.<sup>5</sup> The new model places greater emphasis on the ability of individual patients to initiate and execute their own activities for sustaining life, health, and well-being, and on developing the skills needed to design, execute, evaluate, and modify personal plans for lifestyle changes.<sup>6</sup> A key aspect of the implementation of the model is that self-management interventions are targeted at the patients assigned to the model, who are required to develop skills and behaviors to appropriately manage chronic diseases.<sup>1,3,7</sup> Self-management interventions can be categorized according to delivery strategies, administration settings, study design, or content. In this review, the types of self-management interventions are classified according to the delivery strategy used.<sup>1</sup> Studies have shown that self-management interventions not only improve health outcomes, adherence to treatment recommendations, and the ability to cope with and control disease symptoms,<sup>8,9</sup> but they can also reduce healthcare costs for patients with chronic diseases.<sup>1</sup> However, there are health disparities between patients with chronic diseases, especially between those with limited health literacy (HL) and those with adequate HL. Most of those with limited HL end up with worse health outcomes, lower quality of life (QOL), and an increased cost burden, regardless of whether they received self-management interventions.<sup>9-12</sup> In recent years, this situation has attracted public attention, and it is realized that it requires urgent intervention to save the lives of many patients

with limited HL.

According to the Centers for Disease Control and Prevention (CDC), HL refers to the ability to find, understand, and use information and services to inform health-related decisions and actions for oneself and others. Patients with chronic diseases and limited HL not only have an increased risk of poor health outcomes and higher health care costs, but also have unhealthy self-management behaviors and are dissatisfied with the care they receive.<sup>9-11,13,14</sup> HL significantly affects the uptake and adoption of self-management interventions.<sup>9,11,14,15</sup> The incompatibility of interventions with patients' HL level, culture, and preferences is thought to contribute to the poor uptake and adoption of self-management interventions.<sup>16-19</sup> For instance, mobile health (mHealth) interventions are reported to face an additional challenge in relation to digital HL, which demands particular skills complementary to general literacy and HL.<sup>19</sup> Evidence from recent studies suggests that this situation can be reversed by tailoring self-management interventions to patients' HL and economic levels, preferences, and cultural backgrounds.<sup>19-22</sup>

Despite increasing recommendations for tailoring chronic disease self-management interventions for patients with limited HL, all over the world, evidence of such interventions according to the World Bank classification of countries remains limited. Studies have found limitations in the transferability of interventions from high-income countries to low and middle-income countries.<sup>16-19</sup> As clinicians and researchers are obliged to develop self-management interventions for adults with chronic diseases and limited HL, evidence is needed to guide decision-making on interventions that are relevant for this group of patients.

A search of various databases, including PubMed, EBSCOhost, Cochrane Reviews, HINARI, and PROSPERO, produced no summary of what was known about self-

management interventions for adults with chronic diseases and limited HL. A summary is expected to have important implications for researchers, clinicians, and patients. Researchers and clinicians can use this summary as a guide when they select appropriate self-management interventions for their patients. The patients, in turn, may improve uptake of the interventions and, consequently, improve health outcomes. In light of developing and potentially disparate evidence, a scoping review was deemed the most appropriate type of review to address this particular need for information.

This scoping review aimed to summarize the self-management interventions available for adults in high, middle, and low-income countries who had chronic diseases and possibly limited HL. The review sought to examine whether there were different types of self-management interventions, underpinning frameworks, administration settings, administration timeframes, intervention presenters, intervention outcomes, key findings, and recommendations.

## Methods

**Protocol and registration:** The scoping review protocol was registered with the Open Science Framework (OSF).<sup>23</sup> This review report used the Preferred Reporting Items for Systematic

Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist.<sup>24</sup>

**Eligibility criteria:** A population, concept, and context (PCC) framework was used to refine the inclusion and exclusion criteria, as specified in table 1. The population included adults diagnosed with either one or multiple chronic diseases (chronic cardiovascular, renal, hepatic, pulmonary, musculoskeletal, lymphatic, psychiatric, hematological, immune deficiency, respiratory, and metabolic diseases) at risk for limited HL by default as cited by the author(s), or found to have limited, low, compromised, or inadequate HL by any validated HL test. Self-management intervention is a key concept in this review. It includes types, underpinning frameworks, administration settings, administration timeframe, intervention presenters, outcomes and measurement tools, key findings, and recommendations. The context includes high, middle, and low-income countries.

**Information sources:** A subject librarian systematically searched 13 electronic databases to identify eligible studies. The databases searched were PubMed, and 12 databases searched through EBSCOhost: Academic Search Ultimate, Africa-Wide Information, APA PsycArticles, APA PsycInfo, CINAHL with Full Text, Communication & Mass Media Complete, ERIC, Health Source:

**Table 1. Scoping review inclusion and exclusion criteria**

Element	Inclusion criteria	Exclusion criteria
Population	Adult diagnosed with either one or multiple chronic diseases (chronic cardiovascular, renal, hepatic, pulmonary, musculoskeletal, lymphatic, psychiatric, hematological, immune deficiency, respiratory, and metabolic diseases) At risk for limited HL by default, as cited by the author(s), or found to have limited, low, compromised, or inadequate HL by any validated HL test	Absence of HL assessment results Lack of citation of the risk population with limited HL
Concept	Self-management interventions (types, underpinning frameworks, administration settings, administration timeframe, intervention presenters, outcomes and measurement tools, key findings, and recommendations)	
Context	High, middle, and low-income countries	
Type of evidence sources	Qualitative, quantitative, and mixed methods primary research	Grey literature, reviews, letters to the editor, opinions, and protocols

HL: Health literacy

Consumer Edition, Health Source: Nursing/Academic Edition, Humanities Source Ultimate, MEDLINE, and Sociology Source Ultimate. In addition, we conducted a general Google search for references of eligible studies.

**Search:** A comprehensive search strategy was developed by the research team in collaboration with a subject librarian. Boolean operators were used for the search string. "Search: (Self-manag\* or self-care or "self manag\*" or "self care") AND (delivery n2 (strategies or strategy or mode OR modes OR forms or format or form or type\* OR style\*)) or e-mail\* or email\* or postal or fax or hand-distribut\* or "printed material\*" or brochure\* or pamphlet\* or booklet\* or poster or posters or newsletter\* or infograph\* or internet or sms or "phone call\*" or smartphone or cellphone or "cellular telephone\*" or "personal meeting\*" or "peer group\*" or app or "mobile application\*" or "online resource\*" or telehealth\* or video\* or audio\* or "voice message\*" or "sound recording\*" or "online forum\*" or web\* or "group interven\*" or digital or photovoice or storytelling))) AND ((chronic\* or non-communicable or "non communicable")) AND ((health litera\*)". Neither time nor language restrictions were applied in the search to include the widest possible range of publications.

**Selection of sources of evidence:** After deduplication, titles, abstracts, and full texts were screened against the inclusion and exclusion criteria by two researchers independently of each other. Rayyan software facilitated the process.<sup>25</sup> The full texts of potentially eligible studies were then screened for inclusion, with reasons for exclusion recorded. Any disagreements were resolved through discussion. A PRISMA flow chart was used to summarize the screening and selection process.<sup>26</sup>

**Data charting process:** Two researchers jointly developed and piloted a data-charting form to extract key information from eligible studies. A Google form with all the variables,

as shown in the data-charting form, was developed to simplify the data charting process. The two researchers extracted the data independently, discussed conflicting results, and updated the data-charting form as part of an iterative process.

**Data items:** Data extracted from eligible studies included author(s), year of publication, country of origin (where the study was conducted), study aim, participant characteristics (type of chronic disease and sample size), and study design. In addition, the type of self-management intervention, underpinning framework (theoretical or empirical), administration setting, administration timeframe, intervention presenter, outcomes and measurement tool, key findings, and recommendations were included.

**Synthesis of results:** Data extracted from eligible studies were analyzed based on PCC frequency counts. The population was presented numerically according to sample size and type of chronic disease. The concept was analyzed using frequency count of the self-management intervention types, underpinning frameworks, administration settings, administration timeframe, presenters, outcomes, key findings, and the recommendations. According to the context, frequency counts were performed for the countries where the respective studies had been conducted; countries were classified by income level according to the World Bank classification of countries. The data were presented in tabular form to summarize the evidence found and to answer the review questions.

## Results

**Selection of sources of evidence:** In total, 688 records were identified through database searching; an additional 13 were identified through bibliography searching of initially included studies after the search, which brought the total to 701. After duplicates had been removed, 459 records remained.

These were title and abstract screened – 386 records were excluded by this step. The remaining 72 records with full texts were assessed for eligibility against the inclusion and exclusion criteria; 59 full texts were excluded with reasons listed in the PRISMA flow diagram (Figure 1), and 13 records were included in this review.

**Characteristics of sources of evidence:** The main characteristics of the 13 studies that were eligible for this review are shown in table 2. All studies involved a total of 3522 participants. Most ( $n = 7$ ) studies had been published in the last five years (2017-2022).<sup>27-33</sup> The majority ( $n = 10$ ) of eligible studies were conducted in the United States of America (USA),<sup>27,29-32,34-38</sup> and one study each in Canada,<sup>39</sup> Sweden,<sup>28</sup> and Iran.<sup>33</sup>

Of the 13 included studies, four were randomized controlled trials (RCTs),<sup>27,31,33,35</sup> four were quasi-experiments,<sup>29,30,32,34</sup> two were exploratory qualitative surveys,<sup>28,39</sup> two were quantitative surveys,<sup>36,37</sup> and one had a mixed-method design.<sup>38</sup> The majority ( $n = 4$ ) of studies investigated patients with diabetes,<sup>33,35,36,39</sup> followed by chronic obstructive pulmonary disease (COPD)/asthma ( $n = 3$ ),<sup>28,30,32</sup> and the remaining studies examined patients with congestive heart failure (CHF),<sup>34</sup> hypertension (HTN),<sup>27</sup> human immunodeficiency virus (HIV),<sup>29</sup> coagulopathy,<sup>37</sup> osteoarthritis,<sup>38</sup> and multiple chronic conditions.<sup>31</sup> We did not perform a quality appraisal of the studies, as our objective was to summarize the available evidence on the topic.

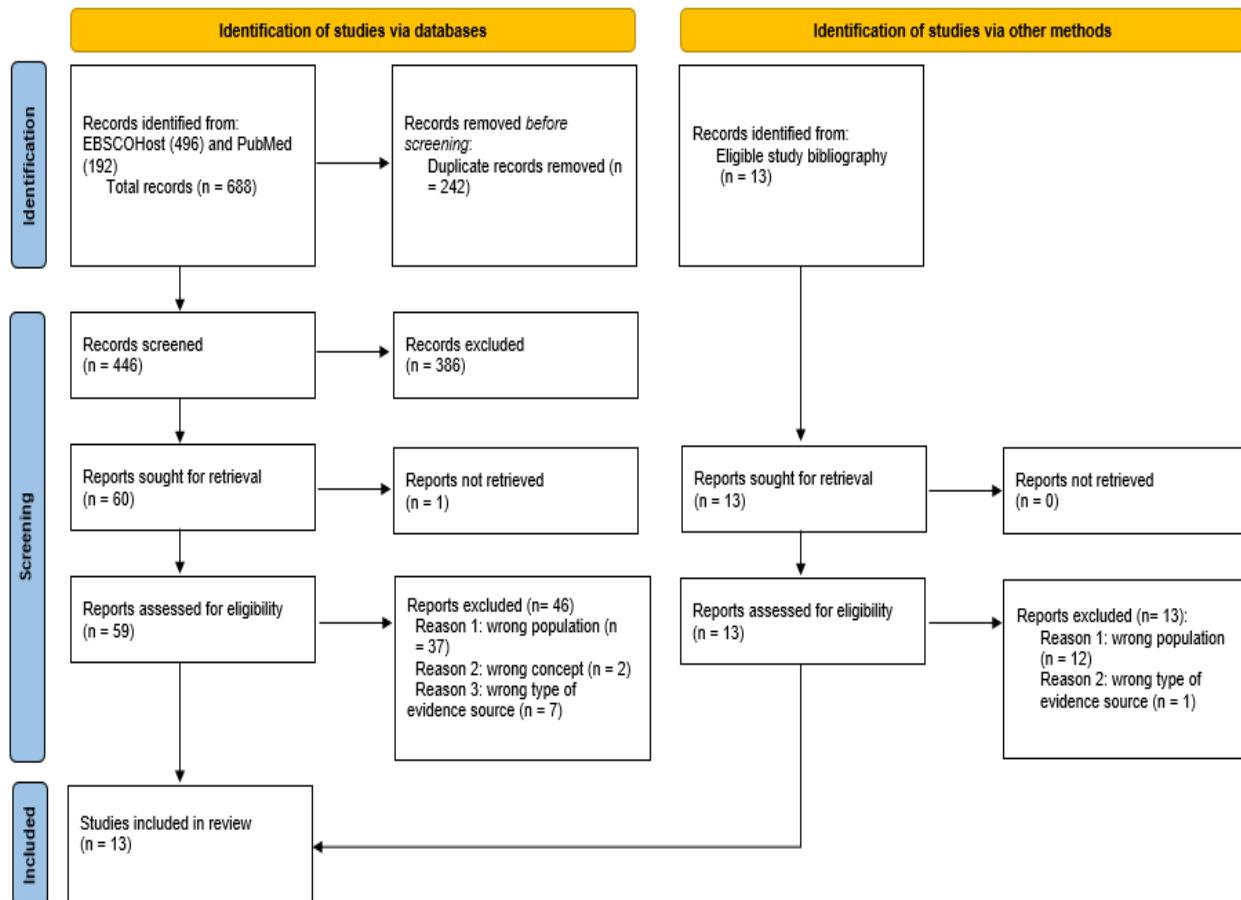


Figure 1. Flow diagram

Table 2. Characteristics of eligible studies

Author(s)	Country	Study aim	Study design	Study participants (disease type and sample size)	Intervention
Al Sayah et al. <sup>39</sup>	Canada	To examine the application of interactive communication loops, the use of jargon, and the impact of HL	Exploratory qualitative	Patients with type 2 diabetes (n = 13)	In-person interactive communication loops
DeWalt et al. <sup>34</sup>	USA	To develop and test the acceptability and efficacy of the intervention	Pre/post pilot study	Patients with CHF (n = 52)	Didactic session, picture-based booklet, follow-up phone calls
Houston et al. <sup>27</sup>	USA	To test an interactive veteran-to-veteran storytelling DVD intervention versus an education-only DVD for enhancing the cultural relevance of the intervention	Multisite RCT	African American veterans with uncontrolled HTN (n = 244)	Storytelling DVD versus didactic-only DVD
Marklund et al. <sup>28</sup>	Sweden	To explore and describe the experiences of an eHealth tool over time and the factors that might affect use	Exploratory qualitative	Patients with COPD (n = 16)	COPD website with videos, written information, images, and helpful links
Mohan et al. <sup>35</sup>	USA	To test the effect of providing illustrated, plain-language medication lists on medication understanding, adherence, and satisfaction	RCT	Latino patients with diabetes (n = 200)	PictureRx illustrated list, plain language bilingual text, and video versus a handwritten list of medications
Nokes and Reyes <sup>29</sup>	USA	To test whether electronic HL increases after participating in one of two brief educational interventions	Non-equivalent quasi-experimental	Patients with HIV (n = 100)	National Library of Medicine video with text and audio, plus a teach-back session
Press et al. <sup>30</sup>	USA	To develop and pilot a V-TTG inhaler skills training module	Pre/post study	Patients with asthma or COPD (n = 6)	V-TTG inhaler skills training module
Sarkar et al. <sup>36</sup>	USA	To examine whether the use of an internet-based patient portal varies	Quantitative survey	Patients with diabetes (n = 2446)	Internet-based patient portal
Schillinger et al. <sup>37</sup>	USA	To explore whether concordance rates vary when patients report their regimen verbally or identify their regimen by use of a visual aid	Quantitative survey	Patients on long-term warfarin (n = 109)	Digitalized colour menu of Coumadin pills and warfarin pills
Sperber et al. <sup>38</sup>	USA	To describe participants' evaluations of a telephone-based, osteoarthritis self-management support intervention	Mixed methods	Patients with osteoarthritis (n = 45)	Written and audio versions of educational materials and phone calls
Sudore et al. <sup>31</sup>	USA	To compare the efficacy of PREPARE plus an easy-to-read advance directive versus an advance directive alone to increase advance care planning documentation and patient-reported engagement	RCT	Patients with ≥ 2 chronic illnesses (n = 202)	Online PREPARE program plus an advance directive

**Table 2. Characteristics of eligible studies (continue)**

Author(s)	Country	Study aim	Study design	Study participants (disease type and sample size)	Intervention
Thomas et al. <sup>32</sup>	USA	To examine whether inhaler training could be delivered using internet-based home videoconferencing, and its effect on inhaler technique, self-efficacy, QOL, and adherence	Pre/post pilot study	Patients with COPD (n = 6)	Internet-based videoconference
Zeidi et al. <sup>33</sup>	Iran	To evaluate the impact of theory-based educational intervention on HL and self-care behaviors	RCT	Patients with type 2 diabetes (n = 83)	Didactic session, pamphlet, and educational booklet

CHF: Congestive heart failure; HL: Health literacy; RCT: Randomized controlled trial; HIV: Human immunodeficiency virus; COPD: Chronic obstructive pulmonary disease; V-TTG: Virtual teach-to-goal; QOL: Quality of life; HTN: Hypertension; DVD: Digital video disk; eHealth: Electronic health

**Results of individual sources of evidence:** The self-management interventions, particularly the type, underpinning framework, administration setting, administration timeframe, presenter, outcomes, key findings, and recommendations in each source of evidence are summarized in table 3. The table also includes author name(s), year of publication, and the country where the study was conducted.

### Synthesis of results

**Types of self-management interventions:** Four main types of self-management interventions, based on the delivery strategies, were identified in the studies. In-person with or without print/electronic educational intervention was used by five studies.<sup>29,31,33,34,39</sup> In this type of intervention, in-person delivery strategies used included interactive communication,<sup>39</sup> a didactic session,<sup>33,34</sup> and a teach-back session.<sup>29</sup> Print educational aids used included educational pamphlets and booklets,<sup>33,34</sup> and National Library of Medicine videos,<sup>29</sup> whereas electronic educational aids included mobile phones<sup>34</sup> and an HIV information website.<sup>29</sup>

The second type of intervention is a print-based educational intervention, which was used by three studies.<sup>27,35,37</sup> Printed educational aids used in this type of intervention included PictureRx illustrated medication accompanied by plain-language bilingual text,<sup>35</sup> a digitized color menu of Coumadin pills and warfarin pills,<sup>37</sup> and a storytelling intervention digital video disk (DVD).<sup>27</sup>

The third type is electronic-based educational intervention, which was used by four studies.<sup>28,30,32,36</sup> Electronic educational aids used included a website that consisted of videos, written information, images, and helpful links,<sup>28</sup> internet-based patient portal,<sup>36</sup> internet-based home videoconference visits,<sup>32</sup> and a virtual teach-to-goal (V-TTG) learning session.<sup>30</sup>

The fourth type of intervention used both

print and electronic educational interventions. This type was found in a study that used written and audio versions of educational materials and telephone calls to deliver interventions.<sup>38</sup>

**Frameworks underpinning self-management interventions:** Ten studies used theoretical or empirical frameworks to guide the development of interventions. Seven studies used empirical frameworks to inform interventions.<sup>27,28,34-39</sup> Only three studies used theoretical frameworks.<sup>30,31,33</sup> The theories used were Bloom's learning theory,<sup>30</sup> cognitive and behavior change theories,<sup>31</sup> and the theory of planned behavior.<sup>33</sup> Three studies did not indicate their underpinning framework.<sup>29,32,37</sup>

**Self-management intervention administration settings:** Three categories of intervention administration settings were identified in the studies included in this review. Six studies were health care facility-based, combined with a home or community setting.<sup>27,30,31,33,34,38</sup> In this category, study participants received their initial interventions at the health care facility and were followed up in their respective homes or communities by health care providers/research team. For instance, DeWalt et al. presented a one-hour education session for participants during a regular clinic visit, and later made seven scheduled follow-up phone calls, on days 3, 7, 14, 21, 28, 56, and 84, to reinforce the education session and to troubleshoot the diuretic dose adjustment protocol.<sup>34</sup>

A session facilitated with a DVD was presented to veterans during clinic visits, and they were later provided with two DVDs to watch at home for a period of six months.<sup>27</sup> Written and audio versions of osteoarthritis educational materials comprising 10 modules were provided during clinic visits and followed up by monthly phone calls to review key points in the modules, develop weekly self-management goals and action plans, and engage in problem-solving.<sup>38</sup>

Table 3. Results of specific self-management interventions

Author(s)	Country of origin	Self-management intervention							Recommendation
		Type	Under-pinning framework	Administration setting	Timeframe	Presenter	Outcome (measurement tool)	Key findings	
Al Sayah et al. <sup>39</sup>	Canada	In-person with or without print/electronic intervention	Empirical	Facility-based alone	46 minutes	Primary care nurses	No intervention-related outcomes are presented	-	Intervention presenters need to develop more effective ways of communicating concepts that are critical to chronic diabetes self-care and management.
DeWalt et al. <sup>34</sup>	USA	In-person with print/electronic educational intervention	Empirical	Facility-based and home/community-based	Three months	Pharmacist or health educator	QOL (Minnesota Living with Heart Failure Questionnaire)	Improved by 10 points	Increase understanding of its impact on ambulatory patients with chronic CHF.
Houston et al. <sup>27</sup>	USA	Print-based educational intervention	Empirical	Facility-based and home/community-based	Six months	Research assistant	Knowledge (developed 15-question scale) Blood pressure (WHO protocol)	No improvement The follow-up mean SBP was lower by 5.5 mmHg in the intervention group compared to the control group.	Explore the mechanism of action for behavior change associated with stories. Explore ways to sustain the experience associated with stories over time. Combine an initial video storytelling intervention with longitudinal components, such as brief text messages written by storytellers.
Marklund et al. <sup>28</sup>	Sweden	Electronic-based educational intervention	Empirical	Facility-based only	15 minutes	Health professionals	Knowledge (COPD assessment test)	Knowledge increased after the intervention.	Consider factors such as motivation, IT comfort, and level of HL when developing interventions. Consider the time when evaluating the potential benefit of eHealth tools aiming at behavioral changes. Introduce the intervention when participants are newly diagnosed with the disease.

Table 3. Results of specific self-management interventions (continue)

Author(s)	Country of origin	Type	Underpinning framework	Administration setting	Timeframe	Presenter	Self-management intervention	Key findings	Recommendation
Mohan et al. <sup>35</sup>	USA	Print-based educational intervention	Empirical	Facility-based only	One week	Research assistants	Perception (anecdotal notes) Hope (anecdotal notes) Confidence (communicative and critical HL) Understanding (Medication Understanding Questionnaire) Satisfaction (self-reported satisfaction) Sustaining medication adherence (Spanish translation of the Adherence to Refills and Medications Scale)	Users shared positive comments about IT tools on the COPD web. Some users reported gaining a sense of hope, as the eHealth tool informed them about the disease. Improved confidence in their ability to manage their disease Increased understanding Patients were very satisfied and reported that the tool was clear and easy to read. Improved adherence sustained over time during the follow-up time frame	Determine the effect of PictureRx medication instructions on medication-taking behavior and clinical outcomes.
Nokes and Reyes <sup>29</sup>	USA	In-person with or without print/electronic educational intervention	Unclear	Facility-based only	One week	Expert HIV nurse clinician	Electronic HL (electronic Health Literacy Scale)	No difference in electronic HL between the two educational interventions	During clinic visits, it is important to teach consumers/patients how to identify a reliable HIV health information website.

Table 3. Results of specific self-management interventions (continue)

Author(s)	Country of origin	Type	Underpinning framework	Administration setting	Timeframe	Self-management intervention		Key findings	Recommendation
						Presenter	Outcome (measurement tool)		
Press et al. <sup>30</sup>	USA	Electronic-based educational intervention	Theoretical (Bloom's learning theory)	Facility-based and home/community-based	Content-dependent	Trained staff	Mastery of inhaler skills (validated V-TTG self-assessment questionnaire)	Participants' confidence in their inhaler skills improved.	Determine whether patients will be willing and able to use post-discharge V-TTG. Determine if at-home V-TTG improves retention of learned inhaler skills and whether this, in turn, leads to improved health outcomes.
							Inhaler misuse (validated V-TTG self-assessment questionnaire)		
Sarkar et al. <sup>36</sup>	USA	Electronic-based educational intervention	Empirical	Home/community-based only	No time limit	Kaiser Permanente Northern California	Accessing and navigating the patient portal (slightly modified version of an instrument validated against direct HL measures)	Post-V-TTG inhaler misuse decreased significantly.	Examine the possible links between patient portal use and processes of care.
Schillinger et al. <sup>37</sup>	USA	Print-based educational intervention	Unclear	Facility-based only	Instant	Research assistants	Activating patient portal (slightly modified version of an instrument validated against direct HL measures)	Participants were unlikely to both access and navigate an internet-based patient portal.	Assessing adherence without assessing regimen concordance may lead to systematic inaccuracies in adherence assessment.
Sperber et al. <sup>38</sup>	USA	Print and electronic-based educational intervention	Empirical	Facility-based and home/community-based	12 months	Health educator	Perception (anecdotal notes)	Participants commonly expressed appreciation for the information received.	Patients need more information about the nature and management of their disease.

Table 3. Results of specific self-management interventions (continue)

Author(s)	Country of origin	Type	Under-pinning framework	Administration setting	Timeframe	Presenter	Self-management intervention	Key findings	Recommendation
Sudore et al. <sup>31</sup>	USA	Electronic-based educational intervention	Theoretical (cognitive and behavioral change theories)	Facility-based and home/community-based	Five years	Research staff	Self-reported general health (developed survey tool) Advance care planning documentation and engagement (developed questionnaire)	Participants had better self-reported general health and had less pain. Intervention resulted in higher advance care planning documentation and engagement than in the control group.	Mitigate literacy and language barriers to advance care planning, enabling patients to start planning on their own.
Thomas et al. <sup>32</sup>	USA	Electronic-based educational intervention	Unclear	Home/community-based only	Three months	Trained pharmacist	Not able to assess outcomes due to the limited number of participants	Comparing the inhaler training approach with other inhaler training interventions	Compare this inhaler training approach with other inhaler training interventions.
Zeidi et al. <sup>33</sup>	Iran	In-person with or without print/electronic educational intervention	Theoretical (theory of planned behavior)	Facility-based and home/community-based	Two months	Researchers	Attitude (self-administered questionnaire) HL (Short Test of Functional Health Literacy in Adults)	The mean score of attitudes of the experimental group improved after the intervention. The number of patients whose HL improved significantly increased.	Intervention presenters need to be familiarized with the concept and strategies of HL and apply these skills while educating patients.

WHO: World Health Organization; COPD: Chronic obstructive pulmonary disease; V-TTG: Virtual teach-to-goal; HL: Health literacy; HIV: Human immunodeficiency virus; CHF: Congestive heart failure; QOL: Quality of life; SBP: Systolic blood pressure; IT: Information technology; eHealth: Electronic health

Sudore et al. facilitated participants to view the PREPARE by answering questions, generating a unique action plan, and making a "summary of my wishes" for participants during a clinic visit; later, the summary was printed and given to participants with the website login to take home. Again, a phone call was made to each participant 1 to 3 days prior to their upcoming primary care visit, to remind them to talk to their clinicians about the PREPARE materials.<sup>31</sup> A multi-part training program that involved five 45-minute training sessions was presented for participants with type 2 diabetes during clinic visits. They were provided with a pamphlet and an educational booklet to take home, as a reminder of the educational content.<sup>33</sup> Patients with HIV watched National Library of Medicine videos during clinic visits and were followed up by a one-week home assignment to evaluate HIV information websites, and 15 minutes of reinforcement and a teach-back session with the expert HIV nurse clinician.<sup>29</sup>

The second most common category of intervention administration setting is a health care facility-based setting only, which was used by six studies.<sup>28-30,35,37,39</sup> Al Sayah et al. examined the application of interactive communication loops and the use of jargon by nurses when providing education and counselling to patients during clinic visits.<sup>39</sup> Interventions were implemented for participants only during regular visits.<sup>28</sup> Participants were oriented to the PictureRx card layout, and they were shown a two-minute video about it during regular clinic visits.<sup>35</sup> Schillinger et al. asked participants to verbalize their weekly warfarin regimen and identify it on a digitalized color menu during clinic visits.<sup>37</sup> A virtual education module was delivered via handheld tablet to participants during clinic visits.<sup>30</sup>

The third category is a home or community-based setting only, which was used by two studies.<sup>32,36</sup> Participants were publicly offered

an internet patient portal by Kaiser Permanente Northern California.<sup>36</sup> Participants were trained in relation to prescribed inhalers in their respective homes via videoconferencing.<sup>32</sup>

***Self-management intervention administration timeframe:*** The timeframe of intervention administration ranged from 15 minutes to five years in all studies included in this review. Health care facility-based studies (n = 6) generally had the shortest timeframes, and ranged from a single 15-minute session to scheduled interactions over a week.<sup>28-30,35,37,39</sup> The four studies involving health care facilities and/or home or community interventions had timeframes ranging from one to six months of planned interactions.<sup>27,32-34</sup> Only two studies had longer timeframes, 12 months and five years, respectively.<sup>31,38</sup>

***Self-management intervention presenters:*** Self-management interventions in the majority (n = 7) of studies included in this review were commonly presented by health care workers,<sup>28-30,32,34,38,39</sup> followed by research team members (n = 5).<sup>27,31,33,35,37</sup> Among health care workers, professional nurses (n = 5) were most often involved,<sup>28-30,38,39</sup> followed by pharmacists (n = 2).<sup>32,34</sup>

***Self-management intervention outcomes and measurement tools:*** Self-management intervention outcomes reported by studies relate to QOL,<sup>33</sup> knowledge and understanding regarding the disease,<sup>28,34,35,37</sup> clinical outcomes,<sup>27,38</sup> and perceptions and attitudes regarding the interventions.<sup>28,33,35</sup> Self-management skills and behaviors<sup>28,30,31,35,36</sup> and HL<sup>29,33</sup> were also reported on.

Various outcome-measurement tools were used by the studies for different types of interventions. DeWalt et al. used the Minnesota Living with Heart Failure Questionnaire (MLHF-Q) to measure the QOL of participants.<sup>34</sup> A COPD assessment test,<sup>28</sup> Medication Understanding Questionnaire (MUQ),<sup>35</sup> a self-developed 15-question scale,<sup>34</sup> and researcher-formulated oral questions<sup>37</sup>

were used to measure knowledge and understanding of the diseases in the studies. The World Health Organization (WHO) blood pressure protocol was used to monitor the blood pressure of study participants,<sup>27</sup> and a developed survey tool was used to assess the self-reported general health of study participants.<sup>38</sup> Perceptions of, attitudes towards, and satisfaction with the interventions were measured by various tools, including anecdotal notes,<sup>28,38</sup> a self-administered questionnaire,<sup>33</sup> self-reports of satisfaction,<sup>35</sup> and the Communicative and Critical Health Literacy (CCHL) Scale.<sup>28</sup> The studies that reported outcomes related to self-management skills and behaviors used various measurement tools, including a Spanish translation of the Adherence to Refills and Medications Scale (ARMS),<sup>35</sup> a slightly modified version of an instrument validated against direct HL measures, the CCHL Scale,<sup>28</sup> a self-developed questionnaire,<sup>31</sup> and the validated V-TTG self-assessment questionnaire.<sup>30</sup> Tools that were employed to measure participants' HL included the electronic Health Literacy Scale (eHEALS)<sup>29</sup> and a Short Test of Functional Health Literacy in Adults (STOFHLA).<sup>33</sup>

### Self-management intervention key findings

**QOL:** Only one study reported on the QOL. DeWalt et al. found that QOL of participants with heart failure had improved after the intervention. They suggest that daily weight measurement and diuretic adjustment, combined with early recognition of symptoms, may prevent the frequent exacerbations seen in this illness.<sup>34</sup>

**Knowledge and understanding:** Four studies reported on knowledge and understanding, with mixed results.<sup>28,34,35,37</sup> Three studies reported that the interventions had been beneficial.<sup>28,35,37</sup> Marklund et al. found that participants' knowledge of how to perform specific exercises and use breathing techniques in their daily lives had increased after the intervention.<sup>28</sup> The intervention was found to

have improved participants' understanding of medication instructions<sup>35</sup> and concordance of treatment regimens.<sup>37</sup> In contrast, one study found that the intervention had no effect on heart-failure-specific knowledge. It is suggested that the intervention focus on improving self-care skill building, rather than general heart failure knowledge, and the measurement tool did not consider this emphasis.<sup>34</sup>

**Health outcomes:** Two studies reported on health outcomes.<sup>27,38</sup> One study reported that an intervention during follow-up to reduce systolic blood pressure (SBP) in participants with HTN had been successful.<sup>27</sup> Sperber et al. found that most participants self-reported improvements in general health and less pain after the intervention.<sup>38</sup>

**Perceptions and attitudes regarding interventions:** Four studies reported on perceptions of and attitudes towards interventions.<sup>28,33,35,38</sup> Two studies found that most participants had positive perceptions of the intervention.<sup>28,38</sup> Some participants were hopeful after the electronic health (eHealth) intervention had informed them about their illness; therefore, they were able to use that knowledge to their advantage.<sup>28</sup> Zeidi et al. found that the average attitude score of the experimental group improved after the intervention.<sup>33</sup> Participants also reported increased satisfaction and confidence in their ability to manage the disease after the intervention.<sup>28,35</sup>

**Self-management skills and behaviors:** Five studies reported on self-management skills and behaviors.<sup>28,30,31,35,36</sup> Positive results were reported by four studies.<sup>28,30,31,35</sup> Marklund et al. found that participants were able to incorporate the advice into their daily lives, and they believed that the eHealth intervention helped them improve their overall situation.<sup>28</sup> Participants' adherence to treatment improved after the intervention and was maintained during follow-up.<sup>35</sup> Studies found that advance care planning

documentation and engagement<sup>31</sup> and confidence in inhaler skills of participants increased after the intervention; in addition, the number of inhaler misuses decreased.<sup>30</sup> In contrast, Sarkar et al. found that, after the intervention, participants were not only less likely to access and navigate an internet-based patient portal, but were also less likely to activate their patient portal accounts and log in with their personal logins and passwords, and less likely to use any functions.<sup>36</sup>

**HL:** Mixed results in relation to HL were reported.<sup>29,33</sup> Zeidi et al. found that the number of participants with improved HL increased after the intervention,<sup>33</sup> whilst for Nokes and Reyes, the intervention had no effect on participants' electronic HL.<sup>29</sup>

### Recommendations from the studies

The recommendations made by the studies included in this review are multifactorial. Despite the benefits of interventions found by studies, four studies emphasized the need for comprehensive and tailored interventions.<sup>28,29,31,37</sup> Other recommendations relate to the need for skilled intervention presenters,<sup>33,39</sup> the need to determine the right time to implement interventions,<sup>28</sup> the use of multiple intervention delivery strategies,<sup>27,32</sup> and shift from a verbal to a visual assessment approach to therapeutic regimen concordance for patients facing communication barriers.<sup>37</sup> Furthermore, exploring the underlying mechanisms causing the effects of the intervention,<sup>27,36</sup> mechanisms for long-term retention of intervention outcomes,<sup>27,30</sup> and validation of intervention effects on multiple outcomes<sup>35</sup> were also recommended by the studies.

### Discussion

**Summary of evidence:** The success of self-management interventions depends on the compatibility of the types of interventions chosen for a particular population, taking into account their culture, HL, and economic

level.<sup>20-22</sup> In this context, this review summarized self-management interventions for adults with chronic diseases who had possible limited HL in countries classified by the World Bank. It is expected that a suitable self-management intervention framework will be proposed based on the reviewed studies. However, the current review found no evidence of specific types of self-management interventions for a similar population in low and middle-income countries, where 86% of global premature deaths related to chronic diseases occur.<sup>40</sup> Most of the types of interventions identified had been applied in high-income countries, which possibly limits transfer to low and middle-income countries. Four main types of self-management interventions were identified according to the interventional delivery strategies used. An in-person with or without print/electronic intervention was the most prominent type,<sup>29,31,33,34,39</sup> followed by electronic-based intervention.<sup>28,30,32,36</sup> Print-based intervention<sup>27,35,37</sup> and interventions using both print and electronic approaches<sup>38</sup> were the other types.

The comprehensiveness of any self-management intervention requires a clear roadmap for its development. It is recommended that both theoretical and empirical frameworks be used to ensure that the intervention is comprehensive.<sup>41-43</sup> However, none of the studies in the current review used both theoretical and empirical frameworks, highlighting the gap that exists. Most studies used empirical frameworks and relied only on concepts derived from previous studies, which may or may not be valid.<sup>27,28,34-39</sup> The gap could also be evidently supported by recurring recommendations that emphasize the need for comprehensive and tailored interventions,<sup>28,29,31,37</sup> skilled intervention presenters,<sup>33,39</sup> determining the right time to implement interventions,<sup>28</sup> and using multiple intervention delivery strategies.<sup>27,32</sup> Therefore,

researchers need to consider this critical aspect when they develop self-management interventions for patients, especially those with possibly limited HL.

The findings of the current review show that the types of self-management interventions used vary across settings. In-person with or without print/electronic interventions were the most common in studies involving two settings, which included health care facilities and home/community settings. Print-based interventions were more common in health care facility-based studies, whilst electronic-based interventions were more common in home or community-based studies. In addition, the review found that the timeframe used to implement the interventions varied across the types of self-management interventions, suggesting that it is a key factor to be considered during intervention development. This argument is supported by the recommendation made in the included studies, namely that time is an important consideration when evaluating the potential benefits of eHealth tools that aim to achieve behavioral change.<sup>28</sup>

It is still debatable whether the type of self-management intervention influences a patient's outcomes. Some scholars found that in-person interventions were associated with better outcomes;<sup>44,45</sup> other scholars failed to find any association between the types and outcomes of self-management interventions.<sup>46,47</sup> In the current review, we also observed some conflicting results for different types of self-management interventions. In-person with or without print/electronic interventions had no effect on knowledge and understanding improvement,<sup>34</sup> whereas paper/electronic-based interventions reported the opposite.<sup>35,37</sup> The results suggest that more research is needed to assess the effects of self-management intervention types on multiple outcomes. This gap is supported by the recommendation made by the studies included

in this review that intervention effects should be evaluated for multiple outcomes.<sup>35</sup>

Even though some scholars reported that intervention presenters had an effect on patient outcomes, other scholars found no relationship.<sup>44,45</sup> In this review, we observed that the type of intervention presenters differed for different self-management intervention types. Health care workers were not commonly used in interventions that used both print and electronic media. The findings suggest that selecting appropriate intervention presenters during intervention development is critical for better outcomes. This argument is supported by the recurring recommendation by the studies, that skilled intervention presenters are crucial for the success of the intervention.<sup>33,39</sup>

**Limitations:** There are some limitations to our review. Grey literature, reviews, letters to editors, opinions, and protocols were excluded from this review, which may have resulted in relevant information being missed. In addition, no attempt was made to contact the authors of the article that was excluded because the full text was not available, which may have resulted in fewer eligible studies. The strengths of our study include its development according to a predefined protocol, application of a systematic and transparent approach to identifying studies, having multiple reviewers at each stage, using Rayyan software for screening articles, and reporting findings according to the PRISMA-ScR.

## Conclusion

The lack of evidence to support self-management interventions for adults with chronic diseases, especially those with limited HL, appears to pose challenges for health care providers. The aim of this scoping review was to summarize the evidence available in the literature, which could be used to guide a future systematic review or the development of self-management interventions for similar

populations. The current review found no specific evidence relating to low and middle-income countries, where most premature deaths from chronic diseases occur. The evidence from high-income countries shows that the types of self-management interventions vary across settings. In-person with or without print/electronic interventions were the most common in studies involving the settings of health care facilities and home/community. Print-based interventions were more common in studies based at health care facilities, whereas electronic-based interventions were more common in studies based on home or community settings. Therefore, further primary studies are recommended to provide evidence of self-management interventions for similar populations in low and middle-income countries.

### Conflict of Interests

Authors have no conflict of interests.

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