

Characteristics of self-care interventions for patients with a chronic condition: A scoping review



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ABSTRACT

Background: Self-care is a fundamental element of treatment for patients with a chronic condition and a major focus of many interventions. A large body of research exists describing different types of self-care interventions, but these studies have never been compared across conditions. Examination of heterogeneous interventions could provide insights into effective approaches that should be used in diverse patient populations.

Objectives: To provide a comprehensive and standardized cross-condition overview of interventions to enhance self-care in patients with a chronic condition. Specific aims were to: 1) identify what self-care concepts and behaviors are evaluated in self-care interventions; 2) classify and quantify heterogeneity in mode and type of delivery; 3) quantify the behavior change techniques used to enhance self-care behavior; and 4) assess the dose of self-care interventions delivered.

Design: Scoping review

Data sources: Four electronic databases – PubMed, EMBASE, PsychINFO and CINAHL – were searched from January 2008 through January 2019.

Eligibility criteria for study selection: Randomized controlled trials (RCTs) with concealed allocation to the intervention were included if they compared a behavioral or educational self-care intervention to usual care or another self-care intervention and were conducted in adults. Nine common chronic conditions were included: hypertension, coronary artery disease, arthritis, chronic kidney disease, heart failure, stroke, asthma, chronic obstructive lung disease, and type 2 diabetes mellitus. Diagnoses that are psychiatric (e.g. schizophrenia), acute rather than chronic, or benefitting little from self-care (e.g. dementia) were excluded. Studies had to be reported in English with full-text available.

Results: 9309 citations were considered and 233 studies were included in the final review. Most studies addressed type 2 diabetes mellitus ($n = 85$; 36%), hypertension ($n = 32$; 14%) or heart failure ($n = 27$; 12%). The majority (97%) focused on healthy behaviors like physical activity (70%), dietary intake (59%),

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and medication management (52%). Major deficits found in self-care interventions included a lack of attention to the psychological consequences of chronic illness, technology and behavior change techniques were rarely used, few studies focused on helping patients manage signs and symptoms, and the interventions were rarely innovative. Research reporting was generally poor.

Conclusions: Major gaps in targeted areas of self-care were identified. Opportunities exist to improve the quality and reporting of future self-care intervention research.

Registration: The study was registered in the PROSPERO database (#123,719).

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What is already known about the topic?

- Self-care is a fundamental element of treatment for patients with a chronic condition and a major focus of many interventions.
- A large body of research exists describing different types of self-care interventions, but these studies have never been compared across conditions.
- Examination of heterogeneous interventions could provide insights into effective approaches that should be used in diverse patient populations.

What this paper adds

- Little attention has been given to studying interventions to promote self-care of psychological symptoms.
- Most studies addressed healthy lifestyle behaviors like physical activity. Technology is not commonly used in self-care interventions.
- Although the management of signs and symptoms is one of the most challenging self-care behaviors for patients, few studies have focused on helping patients manage their signs and symptoms.

1. Introduction

In chronic illness, self-care is a fundamental and integral part of treatment and patients who engage in self-care have significantly improved clinical outcomes, with better quality of life, fewer hospitalizations, and longer survival (N.H. Jonkman et al., 2016). The literature addressing self-care has grown exponentially over the past decade, perhaps due to the availability of self-report instruments (Ausili et al., 2017; B. Riegel et al., 2019; Sedlar et al., 2017) and applicable theories (Baydoun et al., 2018; Riegel et al., 2016; Riegel et al., 2019; Riegel et al., 2012; Vellone et al., 2019). At this point, a large body of research exists describing different types of self-care interventions tested in various conditions (N.H. Jonkman et al., 2016; N.H. Jonkman et al., 2017). Unfortunately, healthcare is compartmentalized in silos with specialties and subspecialties, which often precludes the transfer of information from one specialty to another. Therefore, the opportunity to learn from successful approaches developed and evaluated in another specialty is often missed by researchers and healthcare professionals in clinical practice. This lapse in communicating across specialties may slow scientific progress and ultimately hinder the development of effective interventions that benefit patients in need.

Self-care of chronic illness has been defined theoretically as a process of maintaining health through health promoting practices and managing illness (Riegel et al., 2012). This definition captures the idea that self-care encompasses a variety of behaviors, general and disease specific, in which persons suffering from a chronic illness engage to maintain their physical and emotional stability.

These behaviors (e.g. assure sufficient sleep, take prescribed medications, manage stress, be physically active) are referred to as self-care maintenance. Self-care monitoring refers to the process of monitoring behavior and observing oneself for changes in signs and symptoms. When signs and symptoms occur, people adopt a variety of behaviors to address them, which is referred to as self-care management (B. Riegel et al., 2019). Self-care interventions developed for specific patient groups are heterogeneous in the self-care behaviors targeted (e.g., diet, exercise, medication adherence), the mode of delivery, intervention intensity, and outcomes addressed (Jonkman et al., 2017). This heterogeneity has made it difficult to make evidence-based recommendations for practice. With a clearer view of how investigators are designing self-care interventions, progress would be enhanced (Jaarsma et al., 2020).

The general aim of this scoping review was to provide a comprehensive and standardized cross-condition overview of interventions to enhance self-care in patients with a chronic condition. With a focus on a variety of different chronic conditions, the specific aims of this study were to: 1) identify what self-care concepts and behaviors are evaluated in self-care interventions; 2) classify and quantify heterogeneity in mode and type of intervention delivery; 3) quantify the behavior change techniques used to enhance self-care behavior; and 4) assess the dose of self-care interventions delivered.

2. Methods

2.1. Design

A scoping review was systematically conducted following the methodological framework of Arksey and O'Malley (Arksey and O'Malley, 2005): identify relevant studies; select studies based on pre-defined criteria; extract data; and analyze, summarize and report results. The Preferred Reporting Items for Systematic Reviews and Meta-analyses for Scoping Reviews (PRISMA-ScR) was used to optimize reporting and to enhance fidelity (Tricco et al., 2018). Ethical approval was not needed for this review of existing literature.

2.2. Search strategy

Studies were included if they addressed self-care, as defined in the middle range theory of self-care chronic illness, described above (Riegel et al., 2012). To be included interventions had to address self-care monitoring, given its importance as a bridge between self-care maintenance and management. Interventions also had to involve active engagement of patients in the plan of care. That is, studies involving the passive presentation of information to patients were not considered self-care.

In collaboration with two independent university medical librarians in the Netherlands and the US, we searched four electronic databases – PubMed, EMBASE, PsychINFO and CINAHL from January 2008 through January 2019. These databases were chosen because they include most of the research in the self-care

field worldwide. These dates were chosen because interventions and theory have evolved significantly over recent years; to safeguard our ability to generate generalizable results, we limited the search to the prior 10 years. Medical subject headings (MeSH) and the key words *self-care* or *self-management* were used to guide the searches, which focused on chronic conditions, not healthy populations. We chose nine chronic conditions from the list of conditions published by the Office of the Assistant Secretary for Health (OASH) in the Department of Health and Human Services (HHS) of the United States (Goodman et al., 2013). From this list we deleted asymptomatic conditions (e.g. hyperlipidemia) and diagnoses that are psychiatric (e.g. schizophrenia), acute rather than chronic, and those that benefit little from self-care (e.g. dementia). The nine common chronic conditions used are known to cause significant morbidity and mortality worldwide: hypertension, coronary artery disease (CAD), arthritis, chronic kidney disease (CKD), heart failure (HF), stroke, asthma, chronic obstructive pulmonary disease (COPD), and type 2 diabetes mellitus (DM2). Only randomized controlled trials (RCTs) with concealed allocation to the intervention, comparing a behavioral or educational self-care intervention to usual care or another self-care intervention and conducted in adults were included. Studies had to be reported in English with full-text available (see Appendix 1 for the PubMed search syntax). Reference lists of systematic reviews and those of included studies were hand searched to ensure complete inclusion of relevant studies.

2.3. Study selection

Study selection was done in two steps: 1) title and abstract screening; and 2) full-text screening. Prior to each step, researchers were trained by the project manager (HW) to ensure selection consistency. Thereafter, screening was carefully monitored, and researchers received feedback from the project manager to further enhance the fidelity of screening.

Four researchers (PI, OO, MS, ET) were involved in the initial screening of title and abstract. Working in pairs, one person did the primary review and the other independently checked to ensure uniform application of the inclusion criteria. Each potential study was assigned a value 'include'; 'exclude'; or 'undecided'. Discrepancies were resolved through discussion.

Studies labelled 'undecided' were discussed, but if agreement could not be achieved, a third researcher was consulted to make a final decision.

2.4. Data extraction

Once the eligible studies were identified, each full text was assessed independently by five (PI, OO, MS, IB, JBS) trained researchers. Data were extracted using a standardized data extraction tool that we developed and programmed in Microsoft Access for this specific purpose. This tool was used to guide the reviewers, ensuring uniformity and completeness in extracting all variables and intervention components of interest across all included studies. The tool included the following predefined categories: 1) characteristics such as study size, participants, interventionist(s), setting of intervention delivery, and country; 2) self-care concepts (i.e. self-care maintenance, monitoring and management) and self-care behaviors (e.g. physical activity, diet, smoking cessation); 3) intervention mode (e.g. face-to-face, telephone, technology such as internet or devices), type of delivery; 4) dose (intensity, frequency and duration); and 5) nine behavior change techniques (BCTs), such as goal setting, action planning, feedback, reviewing goals, as defined in the BCT Taxonomy V1 (Michie et al., 2013). These techniques have been shown previously to be associated with behavior change (Michie et al., 2018).

The researchers extracted the data from primary studies and published trial protocols after training and coaching by the project manager. The data extraction was checked by a second researcher and discrepancies were discussed and rectified as a group. The project manager then independently checked the final extracted data to ensure validity.

2.5. Analytic approach

Following data extraction, the data were synthesized and discussed by the research team. After summarizing the study characteristics to provide an overview of the studies included, we explored the self-care behaviors that were targeted, the mode and type of delivery, the behavior change techniques used, and the intervention dose provided across the various chronic conditions.

3. Results

3.1. Characteristics of the studies and interventions

A total of 9309 potential studies were identified, of which 233 studies were included in the final review (Fig. 1). A plurality of included studies focused on DM2 ($n = 85$; 36%), hypertension ($n = 32$; 14%) or HF ($n = 27$; 12%). Few studies were conducted in arthritis ($n = 11$; 5%), CKD ($n = 8$; 3%) or stroke ($n = 4$; 2%). Seventeen studies (7%) included patients with more than one chronic condition. The 233 studies represent 59,950 patients, mean age 59.5 (± 8.3) years, of whom a minority was female ($n = 26,587$; 44%). Study sample sizes ranged from 24 to 2445 patients. Most interventions targeted only patients ($n = 208$; 89%), with the remaining interventions also involving others (e.g. family caregivers, partners, friends, neighbors). The involvement of healthcare professionals was not captured here.

A combination of interventionists delivered most of the interventions, but almost half were delivered by nurses ($n = 109$; 47%). Others involved psychosocial workers (e.g. health coach, psychologist, social worker, $n = 55$; 24%), activity specialists (e.g. tai chi trainer, $n = 45$; 19%), dietitians ($n = 34$; 15%), and lay persons ($n = 17$; 7%). The training of those providing the interventions was mentioned in 55 studies (24%). When it was reported, the training was rarely described in detail and the intensity of training varied widely (range 0.75 to 100 h).

Many interventions were delivered in a healthcare setting ($n = 87$; 37%), followed by the home ($n = 36$; 15%), community ($n = 15$; 6%), research center ($n = 4$; 2%), pharmacy ($n = 2$; 0.9%), and in one study, the workplace. In 58 (25%) studies the setting of intervention delivery was not specified. Studies were predominantly conducted in North America ($n = 96$; 41%), followed by Europe ($n = 61$; 26%) and Asia ($n = 56$; 24%) (Fig. 2). Patients in the comparison arm received usual care ($n = 128$; 55%), additional educational or exercise components ($n = 85$; 36%) or another self-care intervention ($n = 20$; 9%).

3.2. Self-care concepts and self-care behaviors

In total, 60% of the studies included all three concepts of self-care (maintenance, monitoring and management) in their interventions (Table 1). The studies that addressed self-care most thoroughly, (i.e., including all three elements of the process), were studies in CAD (80%) and COPD (79%) patients. A minority of studies included self-care maintenance and monitoring without engaging study participants in self-care management (37%). This type of intervention was mostly observed in studies of hypertension (50%) and HF (41%) patients.

Most studies (97%) included some elements of self-care maintenance in the intervention and a wide variety of behaviors were ad-

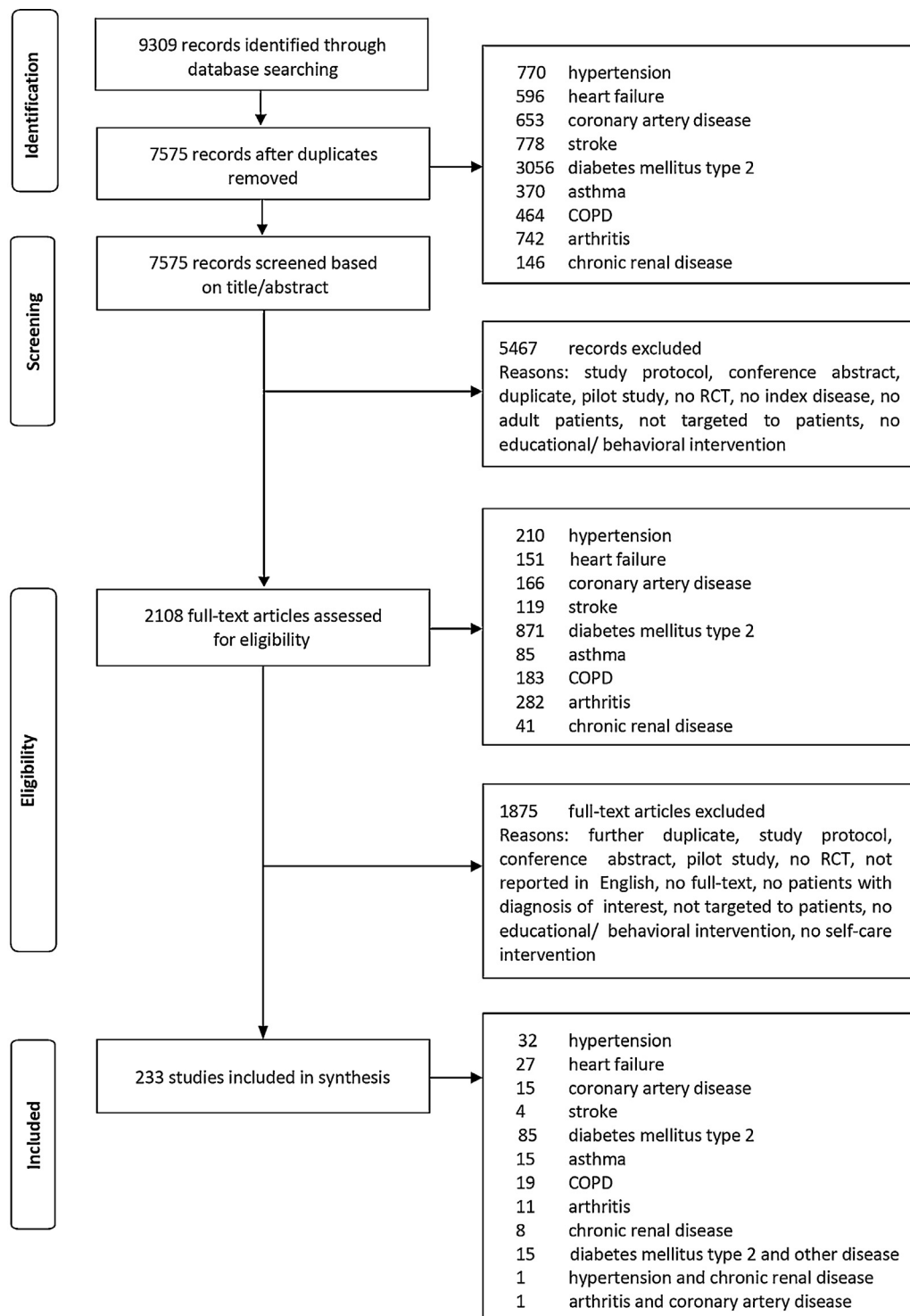


Fig. 1. PRISMA Flowchart of the selection of studies of self-care interventions for patients with a chronic condition.

dressed (Table 1). These maintenance behaviors mainly addressed physical activity (70%), dietary intake (59%), and medication management (52%); these behaviors were included in interventions across all chronic conditions. Between chronic conditions, however, there were large differences in the extent to which self-care maintenance behaviors were included, depending on condition-specific characteristics. To illustrate, studies in DM2 patients mainly focused on physical activity (80%), dietary intake (80%), foot care (17%) and weight control (11%) while the COPD studies mainly

focused on physical activity (78%) and medication management (39%). In 29% of the studies, the specific self-care maintenance behavior was unspecified and described as “lifestyle”. Only a minority of the studies dealt with the psychological or emotional consequences (27%) of having a chronic condition such as mood swings, stress, or depressive symptoms. Psychological consequences were addressed primarily in studies in CAD (46%) and not at all in studies of asthma patients.

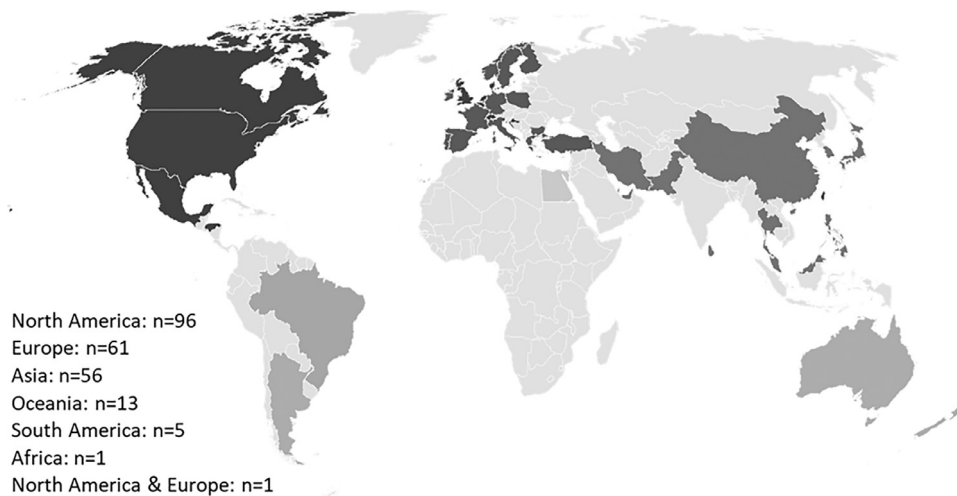


Fig. 2. Geographical distribution of the studies.

Table 1
 Self-care concepts and specific self-care behaviors addressed in the interventions.

Self-care concepts, n (%)	All (n = 233)	DM2 (n = 85)	HT (n = 32)	HF (n = 27)	CAD (n = 15)	COPD (n = 19)	Asthma (n = 15)	Other* (n = 40)
Maintenance and monitoring	85 (36.5)	32 (37.6)	16 (50.0)	11 (40.7)	1 (6.7)	3 (15.8)	4 (26.7)	18 (45.0)
Monitoring and management	8 (3.4)	1 (1.2)	3 (9.4)	0	2 (13.3)	1 (5.3)	1 (6.7)	0
Maintenance, monitoring and management	140 (60.1)	52 (61.2)	13 (40.6)	16 (59.3)	12 (80.0)	15 (78.9)	10 (66.7)	22 (55.0)
Self-care maintenance - self-care behaviors	225 (96.6)	84 (98.8)	29 (90.6)	27 (100)	13 (86.7)	18 (94.7)	14 (93.3)	40 (100)
Physical activity	157 (69.8)	67 (79.8)	14 (48.3)	18 (66.7)	11 (84.6)	14 (77.8)	4 (28.6)	29 (72.5)
Dietary intake	132 (58.7)	67 (79.8)	17 (58.6)	16 (59.3)	9 (69.2)	5 (27.8)	1 (7.1)	17 (42.5)
Medication management	118 (52.4)	51 (60.7)	15 (51.7)	17 (63.0)	5 (38.5)	7 (38.9)	13 (92.9)	10 (25.0)
Lifestyle (unspecified)	65 (28.9)	28 (33.3)	9 (31.0)	13 (48.1)	3 (23.1)	5 (27.8)	1 (7.1)	6 (15.0)
Dealing with psychosocial consequences	60 (26.7)	24 (28.6)	8 (27.6)	8 (29.6)	6 (46.2)	5 (27.8)	0	9 (22.5)
Treatment adherence	49 (21.8)	17 (20.2)	3 (10.3)	8 (29.6)	3 (23.1)	2 (11.1)	5 (35.7)	11 (27.5)
Smoking cessation	31 (13.8)	8 (9.5)	7 (24.1)	4 (14.8)	4 (30.8)	5 (27.8)	1 (7.1)	2 (5.0)
Weight control	23 (10.2)	9 (10.7)	5 (17.2)	2 (7.4)	0	0	1 (7.1)	6 (15.0)
Foot care	16 (7.1)	14 (16.7)	0	0	0	0	0	2 (5.0)
Alcohol use	10 (4.4)	2 (2.4)	4 (13.8)	0	2 (15.4)	1 (5.6)	0	1 (2.5)
Sleep improvement	4 (1.8)	1 (1.2)	0	0	0	0	0	3 (7.5)
Fall prevention	3 (1.3)	1 (1.2)	0	0	0	0	0	2 (5.0)
Breathing exercises	1 (0.4)	0	0	0	0	1 (5.6)	0	0
Self-care monitoring - self-care behaviors	233	85	32	27	15	19	15	40
Symptoms	131 (56.2)	67 (78.9)	2 (6.3)	26 (96.3)	4 (26.7)	9 (47.4)	12 (80.0)	11 (27.5)
Physical activity	103 (44.2)	41 (48.2)	10 (31.3)	6 (22.2)	9 (60.0)	12 (63.2)	2 (13.3)	23 (57.5)
Vital signs	69 (29.6)	9 (10.6)	22 (68.8)	13 (48.1)	1 (6.7)	4 (21.1)	9 (60.0)	10 (25.0)
Dietary intake	47 (20.2)	29 (34.1)	6 (18.8)	3 (11.1)	3 (20.0)	0	0	6 (15.0)
Medication intake	22 (9.4)	11 (12.9)	2 (6.3)	4 (14.8)	0	0	3 (20.0)	2 (5.0)
Psychosocial functioning	11 (4.7)	2 (2.4)	3 (9.4)	0	2 (13.3)	0	0	4 (10.0)
Other behavior (e.g. smoking cessation)	7 (3.0)	1 (1.2)	3 (9.4)	0	1 (6.7)	0	0	2 (5.0)
Unspecified	2 (0.9)	2 (2.4)	0	0	0	0	0	0
Self-care management - self-care behaviors	148 (63.5)	53 (61.6)	16 (50.0)	16 (59.3)	14 (93.3)	16 (84.2)	11 (73.3)	22 (56.4)
Activity changes	70 (47.3)	24 (45.3)	3 (18.3)	5 (31.3)	9 (64.3)	14 (87.5)	4 (36.4)	12 (54.5)
Medication changes	58 (39.2)	22 (41.5)	8 (50.0)	10 (62.5)	3 (21.4)	6 (37.5)	6 (54.5)	3 (13.6)
Dietary changes	44 (29.7)	27 (50.9)	2 (12.5)	4 (25.0)	4 (28.6)	0	1 (9.1)	6 (27.3)
Consulting healthcare provider	36 (24.3)	11 (20.8)	3 (18.8)	8 (50.0)	2 (14.3)	3 (18.8)	5 (45.5)	4 (18.2)
Managing signs and symptoms (unspecified)	21 (14.2)	2 (3.8)	2 (12.5)	5 (31.3)	0	5 (31.3)	6 (54.5)	3 (13.6)
Managing psychosocial consequences	15 (10.1)	5 (9.4)	2 (12.5)	2 (12.5)	2 (14.3)	0	0	4 (18.2)
Breathing exercises	8 (5.4)	0	0	0	0	6 (37.5)	1 (9.1)	1 (4.5)
Pain management	3 (2.0)	0	0	0	0	0	0	3 (13.6)

CAD: coronary artery disease; HF: heart failure; COPD: chronic obstructive pulmonary disease; DM2: diabetes mellitus type 2; HT: hypertension.

* Other diseases include stroke, arthritis, chronic kidney disease or multiple chronic conditions.

Common self-care monitoring strategies addressed blood glucose and body weight in DM2, blood pressure in hypertension, and physical activity, which was addressed in all the chronic conditions. Monitoring of medication intake was included rarely (9%) and done mostly in studies with HF (15%) and asthma (20%) patients. Monitoring of dietary intake was common in studies with DM2 patients (34%) but was not addressed in studies with COPD or asthma pa-

tients. Monitoring of psychological functioning (e.g. mood, stress, depressive symptoms) related to having a chronic condition was rare (5%).

Self-care management behaviors were variable and typically included adapting physical activity (47%), changing medication (39%), and contacting a healthcare provider in response to symptom exacerbation (24%). Dietary changes were advocated in 30% of the

Table 2
Mode and delivery of self-care interventions.

Mode and type of delivery, n (%) [*]	All studies (n = 233)
Face-to-face group	79 (33.9)
Education, advice, and/or instruction	74 (93.7)
Discussion	43 (54.4)
Asking and answering questions	10 (12.7)
Behavioral counseling	33 (41.8)
Face-to-face individual	107 (45.9)
Education, advice, and/or instruction	93 (89.4)
Discussion	30 (28.8)
Asking and answering questions	16 (15.4)
Behavioral counseling	57 (54.8)
Skills training	37 (15.9)
Telephone	122 (52.4)
Calls	107 (91.5)
Texting (e.g. using short message service or app)	17 (14.5)
Self-monitoring tools	233 (100)
Written log or diary	154 (66.1)
Digital log or diary (e.g. smartphone, website)	49 (21.0)
Wearing or using a digital device (e.g. pedometer, glucometer, smartphone)	132 (56.7)
Unspecified	5 (2.1)
Web-based	45 (19.3)
E-mail	6 (13.3)
Online course with feedback	7 (15.6)
E-consultation with a healthcare professional	17 (37.8)
Tele-monitoring by software program	19 (42.2)
Tele-monitoring by healthcare provider	13 (28.9)
Online community for peers	9 (20.0)
Audio/visual/online materials (1-way, without interaction)	41 (17.6)
Digital written materials	7 (17.1)
Video	33 (80.5)
Audio	7 (17.1)
Online program without feedback	6 (14.6)
Printed written materials (1-way, without interaction)	112 (48.1)

* Most interventions include combinations of modes and types of delivery.

studies and most commonly in studies with DM2 patients (51%). Certain disease-specific strategies were used to manage condition-specific signs and symptoms such as pain management in arthritis and breathing exercises in COPD. Some studies (14%) described that patients were taught to “manage their signs and symptoms” (e.g. using action plans of unspecified lifestyle changes), without describing how or what they were taught. Only 15 studies (10%) in DM2, hypertension, HF, CAD, or arthritis addressed managing psychological consequences with techniques such as stress reduction or relaxation.

3.3. Mode and type of delivery

The interventions were delivered using a wide variety of modes (Table 2). Overall, face-to-face group (34%) or individual support (46%) and telephone support (52%) were used most frequently. Most studies used a combination of delivery methods. In group or individual support sessions done face-to-face, the focus was on condition-specific instruction, discussion and counselling to enhance self-care behavior. In 39% of the studies that used telephone calls, the calls were used for intervention reinforcement.

Typical modes of delivery differed across the chronic conditions. Studies with DM2 patients predominantly used multiple methods (e.g., both group and individual face-to-face support combined with telephone support and printed materials). Studies of patients with hypertension mostly included group sessions and telephone contact to enhance self-care and printed materials to reinforce the message. In HF and CAD studies, patients were supported individually, using face-to-face and telephone support and printed materials rather than in-group sessions. Training, such as exercise with a physiotherapist, was mostly done in studies with COPD patients (42%) in addition to face-to-face or telephone support.

Only a small proportion of studies (19%) used technology to deliver the self-care intervention. These technology approaches were used mostly with CAD (33%), COPD (26%), and HF (22%) patients. The primary web-based interventions used e-consultation with a healthcare professional (38%) or telemonitoring (contact by a healthcare professional [29%] or done automatically by software [42%]). In the studies using audio, visual and online materials (18%), videos were used mostly to support, reinforce, or enhance self-care (80%). Studies that were published later in the review period (2015–2019) used 15% (43% versus 28%) more technology to support patient self-care (e.g. web-based support, texting, audio-visual or online materials) compared to studies published before 2015. The use of digital devices to support self-care monitoring increased 9% over time (69% in studies published between 2015 and 2019 versus 58% in the earlier interval).

3.4. Applied behavior change techniques

The nine behavioral change techniques (BCTs) extracted from the studies are shown in Table 3. All the interventions advocated monitoring and recording of self-care behavior, because self-care monitoring was an inclusion criterion. The predominant BCTs used to enhance self-care behavior were goal setting (48%) and problem solving (40%). The specific techniques of action planning, behavioral feedback, and behavioral goal review were used in only a minority of studies (20%–26%). These techniques were most commonly included in studies with DM2 and CAD patients and rarely in studies with hypertension and HF patients. Social support was rarely advised or arranged (7%) and reminders, such as texting to remind patients to take their medication or to be physically active, were used in only 6% of studies. In 20% of the studies, information about health consequences was provided.

Table 3

Applied behavior changes techniques in self-care interventions across the studies ($n = 233$).

Behavior change techniques	n (%)
Self-monitoring of behavior	233 (100)
Goal setting (behavior)	113 (48.1)
Problem solving	92 (39.5)
Action planning	60 (25.5)
Review behavioral goal(s)	54 (23.2)
Feedback on behavior	46 (19.7)
Information about health consequences	46 (19.7)
Social support (unspecified)	17 (7.3)
Reminders	13 (5.6)

3.5. Dose of the interventions

All of the interventions were delivered in multiple sessions, but the number and duration of planned contacts varied widely across modes of delivery. Patients who received training (e.g. physical training with a physiotherapist) had the most contacts and the highest intervention duration (median of 20 contacts covering 20 h of support), followed by web-based support (median of 12 contacts covering 10.5 h of support). Generally, patients received frequent and short telephone contacts (including calls and texting; median 7.5 contacts covering 2 h of support). Group support consisted of (median) 5 sessions covering 8 h and, individual face-to-face support consisted of (median) 4 planned contacts over a substantially shorter timeframe of 2.6 h. Interventions lasted (median) 4.5 months (IQR 3–12; range 0.5–72).

4. Discussion

Our goal in conducting this scoping review was to understand the heterogeneous nature of the interventions used to enhance self-care in patients with a chronic condition and to identify ways to improve self-care interventions based on lessons learned from various conditions. After reviewing the literature from nine different chronic conditions, it is clear that self-care interventions have a mono-disease focus and little knowledge has been shared between scientific communities. Major deficits found in the studies reviewed include a lack of attention to the psychological consequences of chronic illness, technology and behavioral change techniques were rarely used, and few studies focused on helping people manage signs and symptoms.

Few self-care interventions addressed psychological consequences of a chronic illness. This was a surprising finding as adults with chronic illness commonly report feeling anxiety, distress, and depression (Read et al., 2017). Stress in everyday life has been shown to increase mortality risk in adults with chronic illness (Chiang et al., 2018). Clearly, future self-care interventions need to address the psychological ramifications of chronic illness.

Mobile and wireless technologies are increasingly being used across the world (Allida et al., 2020). Based on this, it was surprising to see that technology was not used more routinely in self-care interventions. There is general agreement in the literature that technology can facilitate the provision of personalized, tailored interventions (Burke et al., 2015). Technology can be used to allow more equitable access to care (Hamilton et al., 2018). Technology-based interventions have been shown to produce good outcomes with lower rehospitalization and mortality rates (Aronow and Shamlilyan, 2018), high satisfaction (Buck et al., 2017), and cost savings (Boyne et al., 2013). A growing proportion of the population at all ages uses technology so presumably technology will be used with increasing frequency in the future.

More attention is needed on methods of improving the response to changes in signs and symptoms. Symptoms are the

primary reason why people seek health care (Rutledge and McGuire, 2004) and symptom resolution is an outcome of great interest to health care professionals (Bender et al., 2018). In response to symptoms, it appears that most patients are advised to change their activity level (e.g. rest), take medication, modify their diet, and call a healthcare provider. Yet, advice is rarely sufficient in improving the response to symptoms (Dickson and Riegel, 2009). Very few of the studies focused on skill building exercises, with a focus on skill deficits (e.g., how to read food labels, how to use an inhaler) and ways to manage common and unique situations (e.g., ordering food when eating out, managing diuretics while traveling) through practice and role-playing exercises (Dickson et al., 2014). Further study of this type of intervention is greatly needed.

Although self-care interventions, by definition, address behavioral change, we were surprised that so few of the techniques included in the Behavior Change Technique taxonomyV1 (Michie et al., 2013) were addressed in the self-care interventions. Many of these techniques have been shown to influence behavior (Carey et al., 2019; Connell et al., 2019). It may be that people are using the techniques but not labeling them appropriately (Westland et al., 2018), or we did not identify them (Abraham et al., 2015), or investigators are missing an opportunity to use this rich resource. In future research, we strongly recommend that the BCTs and the associated mechanisms of action be used to support self-care interventions.

It should be noted that interventions are developed for a specific condition, using the terminology that is common within that scientific community. Self-care is the term predominately used in HF, but self-management is predominately used in DM2, CAD, COPD, asthma, and arthritis. In other conditions, such as in hypertension and CKD, the terms are used interchangeably or neither term is used while the behavior is described as part of disease management. This discrepancy may be due to early adoption of the self-management theories of Bandura and Lorig (Lorig et al., 1999) vs. early adoption of the self-care theory of Orem (Orem, 1985). Much has been written about the subtle differences between the concepts (Matarese et al., 2018), and it would be useful to achieve some consensus on when and how to use the terms. At the very least, the person using the term should define what they mean by it because failure to use precise terminology may be keeping the scientific communities in silos (Jaarsma et al., 2020).

Finally, reporting of the intervention components and procedures was often poor. Authors rarely described training of the interventionists. When training was reported, training intensity varied widely and was often too brief to adequately deliver a complex intervention. Intervention fidelity was rarely discussed. We encourage authors to standardize the reporting of future interventions (Jaarsma et al., 2020).

To the best of our knowledge, this is the first review to systematically examine self-care interventions in a variety of heterogeneous chronic conditions. As such, the sample size was large, and the methods were rigorous. Despite these strengths, the review is limited by including only the past 10 years, studies published in English, and exclusion of chronic conditions that might have strong self-care needs. Although we worked with two experienced librarians, we may have missed some relevant studies. Our analysis was based on the information available in the studies and their published protocols, if available, but we may have missed some intervention characteristics due to a poor description. Extensive training and effort were required to align the interpretations of poorly described data. To do so required a team of researchers to complete the work, which introduced complexity that may have introduced error. However, all the data were checked by the project manager, so we are confident that the results presented here are highly accurate.

Based on this scoping review of 233 published clinical trials of self-care interventions, we conclude that investigators continue to emphasize those healthy lifestyle behaviors intended to maintain physical stability (self-care maintenance) without attention to higher-level skills such as symptom management behaviors (self-care management). Little emphasis is given to psychological factors. Although we hoped to find a number of novel approaches tested in different patient populations, what we found was that investigators across conditions have developed and tested standard approaches with little innovation. Technology and behavior change techniques were rarely used. Many interventions were not sufficiently described in the detail needed for replication and implementation by others (Jaarsma et al., 2020). Opportunities exist to improve the innovation of future self-care intervention research.

CRedit authorship contribution statement

BR and TJ conceptualized the project with input from HW and JCAT. HW was responsible for project management with oversight by BR, TJ, and JCAT. The individuals involved in data extraction and validation were HW, PI, IB, JBS, MAS, OO, and ET. BR, TJ, AS, EV and HW were involved in data analysis and interpretation. BR and HW wrote the first draft of the manuscript. All authors were involved in editing and approving the manuscript.

Data Sharing Statement

No additional data available.

Dissemination to participants and related patient and public communities: The authors intend to disseminate this research through social media, press releases to mainstream media, media interviews, and direct dissemination to health professionals in various roles.

The lead author (BR) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as originally planned and registered have been explained.

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Declaration of Competing Interest

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Appendix 1. Search syntax for PubMed

```
("chronic disease"[MeSH] OR "chronic disease*" [Title/Abstract] OR "chronic illness*" [Title/Abstract] OR "chronic condition*" [Title/Abstract] OR "non communicable disease*" [Title/Abstract] OR "noncommunicable disease*" [Title/Abstract] OR "chronically ill" [Title/Abstract])
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OR (essential hypertension[MeSH] OR hypertension[Title/Abstract] OR
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hypertensive[Title/Abstract] OR "high blood pressure*" [Title/Abstract]) OR
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OR ("heart failure"[MeSH] OR "heart failure" [Title/Abstract] OR CHF[Title/Abstract] OR HF [Title/Abstract] OR "cardiac failure" [Title/Abstract] OR "heart decompensation" [Title/Abstract])
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OR ("coronary artery disease"[MeSH] OR "coronary artery disease*" [Title/Abstract] OR "coronary arteriosclerosis" [Title/Abstract] OR "coronary atherosclerosis*" [Title/Abstract] OR "angina pectoris" [Title/Abstract] OR "CAD" [Title/Abstract] OR "heart disease*" [Title/Abstract] OR "myocardial infarction*" [Title/Abstract] OR "unstable angina*" [Title/Abstract] OR "angor pectoris" [Title/Abstract] OR "coronary thrombosis" [Title/Abstract] OR "acute coronary syndrome*" [Title/Abstract] OR "myocardial ischemia*" [Title/Abstract] OR "myocardial ischaemia*" [Title/Abstract])
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OR (stroke[MeSH] OR stroke* [Title/Abstract] OR hemiplegia[MeSH] OR hemiplegia [Title/Abstract] OR hemiplegias [Title/Abstract] OR paresis [MeSH] OR
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paresis [Title/Abstract] OR "cerebrovascular trauma" [MeSH] OR "cerebrovascular trauma" [Title/Abstract] OR "cerebrovascular accident*" [Title/Abstract] OR CVA* [Title/Abstract] OR apoplexy* [Title/Abstract])
```

```
OR (arthritis [MeSH] OR arthritis [Title/Abstract] OR rheuma* [Title/Abstract] OR osteoarthritis [MeSH] OR osteoarthritis [Title/Abstract] OR arthritides [Title/Abstract] OR polyarthritis [Title/Abstract] OR polyarthritides [Title/Abstract])
```

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OR (asthma [MeSH] OR asthma [Title/Abstract] OR "status asthmaticus" [Title/Abstract] OR "bronchial hyper reactivity" [Title/Abstract] OR asthmatic [Title/Abstract] OR wheez [Title/Abstract] OR bronchial* [Title/Abstract] OR "obstructive lung disease*" [Title/Abstract])
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OR ("renal insufficiency, chronic" [MeSH] OR "chronic renal insufficiency" [Title/Abstract] OR "chronic kidney failure" [Title/Abstract] OR "chronic renal failure" [Title/Abstract] OR "chronic renal disease*" [Title/Abstract] OR "chronic kidney disease*" [Title/Abstract] OR "chronic kidney disorder*" [Title/Abstract] OR CKD [Title/Abstract] OR ESRD [Title/Abstract] OR CRD [Title/Abstract] OR "chronic kidney insufficiency" [Title/Abstract])
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OR ("pulmonary disease, chronic obstructive" [MeSH] OR "chronic obstructive pulmonary disease*" [Title/Abstract] OR "chronic bronchitis" [Title/Abstract] OR COPD [Title/Abstract] OR "chronic obstructive airway disease" [Title/Abstract] OR "chronic airflow obstruction" [Title/Abstract] OR "chronic
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obstructive lung disease"[Title/Abstract] OR emphysema[Title/Abstract])

OR ("diabetes mellitus"[MeSH] OR "diabetes mellitus"[Title/Abstract] OR "diabetes mellitus, type 2"[MeSH] OR "diabetes mellitus type 2"[Title/Abstract] OR "insulin resistance"[MeSH] OR "insulin resistance"[Title/Abstract] OR DMII[Title/Abstract] OR DM2[Title/Abstract] OR IDDM[Title/Abstract] OR NIDDM[Title/Abstract] OR "noninsulin dependent"[Title/Abstract] OR "impaired glucose tolerance" [Title/Abstract] OR "impaired glucose tolerant" [Title/Abstract])

AND ("self-management"[MeSH Terms] OR self manag[Title/Abstract] OR self managable[Title/Abstract] OR self managment[Title/Abstract] OR self manage[Title/Abstract] OR self manageable[Title/Abstract] OR self managed[Title/Abstract] OR self manager[Title/Abstract] OR self managerial[Title/Abstract] OR self managers[Title/Abstract] OR self manages[Title/Abstract] OR self managing[Title/Abstract] OR "self care"[MeSH Terms] OR self care[Title/Abstract] OR self caring[Title/Abstract] OR "health education"[MeSH Terms] OR "patient education as topic"[MeSH Terms] OR "patient education"[Title/Abstract] OR "behavior therapy"[MeSH Terms] OR "behavior therapy"[Title/Abstract] OR "behavior therapy"[Title/Abstract] OR self monitor[Title/Abstract] OR self monitor's[Title/Abstract] OR self monitorable[Title/Abstract] OR self monitored[Title/Abstract] OR self monitoring[Title/Abstract] OR self monitors[Title/Abstract] OR self-administration[Title/Abstract] OR self- medication[Title/Abstract] OR "action plan*" [Title/Abstract] OR patient centered[Title/Abstract] OR patient centeredness[Title/Abstract] OR patient centeredness[Title/Abstract] OR patient centering[Title/Abstract] OR patient centrality[Title/Abstract] OR patient centered[Title/Abstract] OR "patient centered approach"[Title/Abstract] OR patient centredness[Title/Abstract] OR patient centric[Title/Abstract] OR patient centricity[Title/Abstract] OR patient centring[Title/Abstract] OR patient centrism[Title/Abstract] OR patient focus[Title/Abstract] OR patient

focused[Title/Abstract] OR patient focusing[Title/Abstract] OR patient focussed[Title/Abstract] OR empowerment[Title/Abstract] OR "self efficacy"[Title/Abstract] OR "self efficacy"[MeSH])

AND ("randomized controlled trial"[Publication Type] OR "randomised controlled trial"[Title/Abstract] OR "randomized controlled trial"[Title/Abstract]

OR "controlled clinical trial"[Publication Type] OR "clinical trial*" [Title/Abstract] OR "random allocation"[MeSH] OR "random allocation"[Title/Abstract] OR "randomly allocated"[Title/Abstract] OR "evaluation studies"[Publication Type] OR "evaluation studies"[Title/Abstract] OR "evaluation study"[Title/Abstract] OR "intervention studies"[Title/Abstract] OR "intervention study"[Title/Abstract] OR RCT[Title/Abstract])

NOT (pediatric* OR pediatric* OR children OR child)

Limits: publication date: 2008

--2019 ("2008"[Date - Publication]: "2019"[Date - Publication])

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