Self-care management of bothersome symptoms as recommended by clinicians for patients with a chronic condition: A Delphi study

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ABSTRACT

Background: Chronically medically ill patients often need clinical assistance with symptom management, as well as self-care interventions that can help to reduce the impact of bothersome symptoms. Experienced clinicians can help to guide the development of more effective self-care interventions.

Objective: To create a consensus-based list of common bothersome symptoms of chronic conditions and of self-care management behaviors recommended to patients by clinicians to reduce the impact of these symptoms.

Methods: A two-round Delphi study was performed among an international panel of 47 clinicians using online surveys to identify common and bothersome symptoms and related self-care management behaviors recommended to patients with heart failure, chronic obstructive pulmonary disease, asthma, type 2 diabetes, or arthritis.

Results: A total of 30 common bothersome symptoms and 158 self-care management behaviors across the five conditions were listed. Each chronic condition has its own bothersome symptoms and self-care management behaviors. Consensus was reached on the vast majority of recommended behaviors.

Conclusions: The list of common bothersome symptoms and self-care management behaviors reflect consensus across four countries on many points but also disagreement on others, and a few recommendations are inconsistent with current guidelines. Efforts to encourage clinicians to recommend effective self-care management behaviors may reduce symptom impact in chronically ill patient populations.

Introduction

The number of individuals suffering from one or multiple chronic conditions is increasing worldwide and causing more than 70% of all deaths globally.[1,2] These non-communicable or long-term chronic conditions caused by genetic, physiological, environmental, and behavioral factors are characterized by a long duration, a progressive trajectory, and long-term medical attention and management.[3,4] Self-care is important in the management of long-term conditions. According to the Middle-Range Theory of Self-Care of Chronic Illness, self-care refers to a process of maintaining health through health-promoting practices and managing illness.[5] Key dimensions of self-care include maintenance (behavior to maintain physical and emotional stability), monitoring (observing for changes in signs and symptoms), and `management (response to signs and symptoms when they occur).[5] Self-care can improve patient-reported outcomes, reduce healthcare utilization, and decrease mortality.[6−8]

People with chronic conditions often experience bothersome symptoms, such as shortness of breath or dizziness. Symptoms are subjective detections of underlying bodily changes that may vary
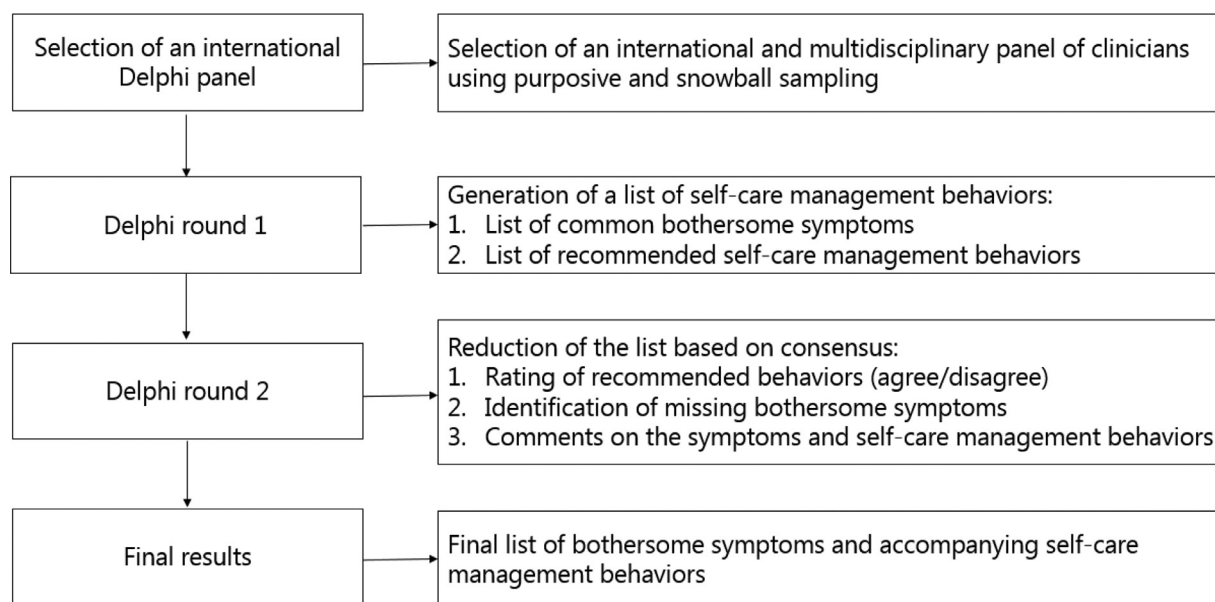
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Fig. 1. Design of the Delphi study.

over time.[9] Bothersomeness reflects the subjective interpretation of patients that the symptom affects their daily life. Early detection of bodily changes and a rapid response to symptoms helps to reduce the impact of bothersome symptoms on patients' life and disease worsening.[9,10] How people respond to their symptoms depends on several factors, such as their knowledge, experiences, cultural norms, attention, cognitive status, support from others and access to care.[5] Clinician support can help patients manage their symptoms more effectively.[3] An essential part of clinician support consist of trying to improve patients' self-care management by equipping patients with skills to actively manage their symptoms.[5] Clinicians routinely recommend to patients what to do when experiencing a specific symptom. The desirable behaviors are often related to the particular condition, symptom severity, cause, and nature of the symptoms.[5] Behaviors can entail independent actions such as taking an extra diuretic when experiencing shortness of breath in heart failure, while others require consultation with a clinician.

Little is known about which self-care management behaviors are recommended by clinicians and even less is known about whether clinicians in different countries provide different recommendations to their patients. This knowledge is important for guiding the development of more effective self-care interventions and improving the clinical support of self-care management behaviors of patients with a chronic condition.

The aim of this study was to create a consensus-based list on common bothersome symptoms of chronic conditions and of self-care management behaviors that clinicians recommend to patients to reduce the impact of these symptoms. It focused on clinicians' recommendations for five common chronic conditions: heart failure (HF), chronic obstructive pulmonary disease (COPD), asthma, diabetes mellitus type 2 (DM2), and arthritis. These conditions were chosen because they often present with frequent and bothersome symptoms (e.g., cough, pain).

Methods

Design

We conducted a Delphi study of clinicians across four countries (Italy, the Netherlands, Sweden, and the United States (US)) to create a consensus-based list of bothersome symptoms and related self-care management behaviors that clinicians recommend to patients. We solicited and synthesized expert opinion over two rounds of surveys of a sample of clinicians whose responses remained anonymous to each other.[11] The processes of data collection and analysis are shown in Fig. 1. The study was approved by the Institutional Review Board of the University of Pennsylvania.

Participants

To ensure diversity of perspectives, we generated a multidisciplinary and international Delphi panel of clinicians.[11,12] It included physicians, occupational therapists, nurse practitioners, and nurses.

Clinicians were purposely selected through the professional network of the research team, clinics that care for chronically ill adults, and snowball sampling. For each of the four countries, a minimum of five clinicians for each of the following common chronic conditions: HF, COPD, asthma, DM2, and /or arthritis, were invited. Inclusion criteria were: (i) expertise in clinical care for adults with HF, COPD, asthma, DM2, and /or arthritis, (ii) working at least part-time in the last three months in a clinical setting for adults with HF, COPD, asthma, DM2, and /or arthritis, and (iii) able to complete the survey in Italian, Dutch, Swedish, or English. An e-mail with study information and a link to the Qualtrics survey (Provo, UT) was sent via email to potential participants. Participants were informed that responses provided in the round 1 survey would be shared in round 2 as a collective list, but that their identity would remain anonymous to other participants throughout the study. For the snowball sampling, participants were asked at the end of the first survey to recommend eligible colleagues to participate. A member of the study team then invited their colleague(s) by email to participate in the study. Participants received a reminder e-mail within two weeks. The Delphi survey was conducted between December 2020 and April 2021.

We aimed to include a panel of 15 experts per chronic condition, since this sample size is considered to provide sufficient diversity.[13]

Delphi rounds

The Delphi survey consisted of two rounds.[11,12] In round 1, we sought to identify common bothersome symptoms and generate an exhaustive list of self-care management behaviors for these symptoms. In round 2, we aimed to reduce this list to the self-care management behaviors for which at least 75% of clinicians agreed with

the recommendation. An agreed-upon definition of consensus for conducting a Delphi study is lacking. The cutoff point of 75% was chosen prior to data collection, as suggestions for consensus have ranged from 51% to 100%.[12]

Round 1 survey - data collection

First, we collected data on demographic and occupational characteristics (age, gender, highest level of education, years of experience caring for adults with a chronic condition, current primary role, and employment setting). Second, we provided participants with two open-ended prompts for each chronic condition: (i) list up to five of the most common bothersome symptoms that patients with this condition experience, and (ii) list self-care management behaviors that you recommend to patients for this symptom. There was no limit to how many self-care management behaviors a participant could list. Participants were asked to respond only for the conditions that they cared for routinely. For example, one clinician may have completed the survey for one condition, while another clinician may have completed the survey for all five conditions.

Round 1 survey − data analysis

SPSS version 26 (IBM Corporation, Armonk, NY, USA) was used for the analyses. We used descriptive statistics to analyze the demographic data. All survey responses from respondents in Italy, the Netherlands, and Sweden were translated into English by bilingual members of the study team (AS, EV, HW, and TJ). Responses were aggregated by two researchers (BR and SP) to generate a list of bothersome symptoms with accompanying self-care management behaviors for each condition. Similar self-care management behaviors were merged to reduce redundancy and wording was rephrased to improve clarity. We aimed to generate an exhaustive list of self-care management behaviors for the clinical experts to review in round 2. Therefore, BR and SP reviewed the North American Nursing Diagnosis Association (NANDA) International Nursing Diagnoses, the Nursing Interventions Classification (NIC), and conducted an internet search of patient education resources (e.g., MedlinePlus) to identify additional self-care management behaviors.[14−16] The aggregated list was reviewed (AS, EV, HW, and TJ) and any disagreements were resolved via discussion in the research team. The list of bothersome symptoms and self-care management behaviors were then translated into Italian, Dutch, and Swedish for round 2 of the Delphi survey (AS, EV, HW, and TJ).

Round 2 survey − data collection

In the round 2 survey, we listed the bothersome symptoms for each condition that was identified in round 1. First, we displayed the self-care management behaviors for each symptom and asked participants to rate if they recommend the behavior to patients when they experience that symptom. Second, we asked participants to identify any additional self-care management behaviors for the symptoms and provide overall comments on the list of symptoms or self-care management behaviors. As in round 1, participants were asked to respond only for the conditions that they cared for routinely.

Round 2 survey − data analysis

We calculated the percent agreement for each self-care management behavior by dividing the number of participants who indicated that they agreed by the total number of participants per chronic condition. Self-care management behaviors that received at least 75% agreement were retained. Similar self-care management behaviors were discussed and merged to reduce redundancy, and wording of self-care management behaviors was rephrased to improve clarity (AS, EV, HW, and TJ).

The comments provided by the participants were qualitatively analyzed. First, all comments were translated into English (AS, EV, HW, and TJ). Second, the comments were reviewed to determine if any additional self-care management behaviors should be added to the list (BR and SP). Third, meaningful comments on ratings were identified and summarized (BR, HW, MR, SP, and TJ).

Results

Demographic characteristics

Demographic characteristics of the Delphi panel are shown in Table 1. In total, 112 clinicians were invited to participate and 47 clinicians completed the Delphi round 1 survey (response rate 42%).

Table 1
Demographic characteristics of the Delphi panel (*n* = 47).

Characteristics	n (%)
Gender	
Male	9 (19)
Female	38 (81)
Age (years)	
20−30	5 (11)
31−40	16 (34)
41−50	8 (17)
51−60	13 (28)
61−70	5 (11)
Highest level of education	
Associate degree	2 (4)
Bachelor degree	15 (32)
Master degree	11 (23)
DNP	9 (19)
MD	5 (11)
PhD	5 (11)
Experience in caring for adults with chronic conditions (years)	
0−5	8 (17)
6−15	23 (49)
16−25	8 (17)
26−35	5 (11)
>35	1 (2)
Missing	2 (4)
Primary current role	
Registered Nurse	20 (43)
Nurse practitioner or nurse practitioner in training	20 (43)
Physician	6 (13)
Occupational therapist	1 (2)
Employment setting	
Both inpatient and outpatient	16 (34)
Outpatient only	19 (40)
Inpatient only	11 (23)
Unknown	1 (2)
Area of expertise*	
Heart failure	26 (55)
COPD	17 (36)
Asthma	12 (26)
Diabetes mellitus type 2	23 (49)
Arthritis	6 (13)
Country	
Italy	13 (28)
The Netherlands	15 (32)
Sweden	12 (26)
US	7 (15)

Abbreviations: DNP: Doctor of Nursing Practice; MD: medical doctor.
*Clinicians could be experienced in multiple conditions.

Reasons for nonresponse were maternity leave, not working clinically, limited time for participation, and unspecified.

Most respondents were European (85%), female (81%) and had a background in nursing (86%). Age, educational background, experience, clinician type (e.g., nurse, physician), and setting varied greatly. Most clinicians were experienced in one condition ($n = 27$) and were involved in the care of patients with HF ($n = 26$), whereas only 6 clinicians were involved in arthritis care.

The second Delphi round was completed by 30 of 47 clinicians (response rate, 64%). Reasons for non-response were limited time for participation and unspecified.

Round 1 survey

In total, 30 bothersome symptoms were identified across the five chronic conditions (see Table 2). Most symptoms ($n = 23$) were condition specific, (e.g., swelling in HF and joint pain in arthritis). Fatigue/tiredness was identified as a bothersome symptom for all the chronic conditions. There were more common bothersome symptoms identified in HF ($n = 12$) and DM2 ($n = 11$) compared with the other chronic conditions. The clinicians paired their recommended self-care management behaviors with each of the identified symptoms; see Fig. 2 and Table 3.

Table 2
Bothersome symptoms of chronic conditions across the five conditions.

Symptom	Chronic condition				
	HF	COPD	Asthma	DM2	Arthritis
Chest pain	X				
Coughing		X	X		
Cramps in lower limbs				X	
Decrease in urine	X				
Diarrhea/constipation				X	
Dizziness	X			X	
Fat accumulation at insulin injection site				X	
Fatigue/tiredness	X	X	X	X	X
Fever	X				
Foot wounds				X	
Gum problems				X	
High blood pressure				X	
Hyperglycemia symptom cluster *				X	
Hypoglycemia symptom cluster **				X	
Hypoxemia (O2 < 88%)		X			
Joint pain					X
Joint stiffness					X
Joint swelling, redness, and/or warmth					X
Loss of appetite	X	X			
Physical limitation/activity limitation					X
Poor sleep quality	X				
Sensitivity to touch and vibration				X	
Shortness of breath	X	X	X		
Shortness of breath, acute		X	X		
Shortness of breath while lying down	X				
Swelling	X				
Swollen belly	X				
Thirst	X				
Weight gain	X				
Wheezing		X	X		

* Frequent urination, increased thirst, blurred vision/acute change in sight, fatigue/listless/general malaise, headache, dry mouth.
** Shakiness, dizziness, sweating, hunger, blurry or double vision, paleness, headache, general malaise, acute tiredness, tingling in the mouth.
Abbreviations: HF, heart failure; COPD, chronic obstructive pulmonary disease; DM2, diabetes mellitus type2.

Round 2 survey

The results of Delphi round 2 are shown in Fig. 2 and Table 3.

The final list consists of 158 out of the 202 (78%) identified self-care management behaviors divided among 30 identified bothersome symptoms of HF, COPD, asthma, DM2, and arthritis.

Most behaviors ($n = 151$; 75%) of round 1 were considered relevant with consensus ($\geq$75% agreement) and were included in the final list. All behaviors without consensus (<75% agreement) were removed ($n = 40$; 20%). Most of the divergence was found in HF ($n = 15$) and DM2 ($n = 14$). Consensus was reached on 8 of 11 recommended behaviors that were added based on review of NANDA, the NIC, and an internet search of patient education resources. Four behaviors that reached consensus were removed due to overlap with similar behaviors (e.g., stand up slowly and avoid quick movements) or because the behavior comprised a step in the decision-making process (e.g., evaluate possible causes). The comments of clinicians resulted in the addition of seven behaviors to the final list. These behaviors were mentioned by multiple clinicians (e.g., check blood pressure) and/or were consistent with recommendations for other symptoms (e.g., contact health care provider). No more bothersome symptoms were suggested in round 2.

Some clinicians commented on their ratings. The meaningful comments were summarized in two topics: (1) Tailoring recommended behavior to the cause of the symptom, patient's situation, and clinician's preference and (2) Discrepancies in recommended behaviors, see Table 4.

Discussion

To the best of our knowledge, this is the first study of clinicians' recommendations for self-care behaviors intended to reduce the impact of common bothersome symptoms of HF, COPD, asthma, DM2, and arthritis. Based on two Delphi rounds, we identified 30 common bothersome symptoms and 158 self-care management behaviors that are endorsed by clinicians for patients to implement in their daily lives.

This extensive list emphasizes the complexity of self-care and self-care management behaviors for both patients and clinicians. Each chronic condition has its own bothersome symptoms and self-care management behaviors. Only two bothersome symptoms (fatigue and shortness of breath) are common in multiple conditions. The similarity and diversity of symptoms and behaviors is especially challenging for patients with multimorbidity. When they experience a symptom, these patients may be expected to figure out which condition it is due to and to choose the symptom management behavior(s) that fits that condition. However, it is not necessarily realistic to expect patients to be able to divine the causes of their symptoms and to tailor their self-care behaviors accordingly. Clinicians play an important role in supporting patients with multimorbidity regarding decision-making about how to manage these symptoms. They can support patients in prioritizing self-care management behaviors based on the dominant condition, and help them to resolve contradictory or ineffective symptom management recommendations from multiple clinicians.[17−19] Although clinicians tend to focus too narrowly on the conditions that are within their expertise, it is important to take comorbidities into account and collaborate with other clinicians that are involved in treating comorbid conditions.[17] In addition, clinicians should collaborate with patients when choosing the treatment that best fits their needs and preferences. Both the clinician's medical expertise and the patient's knowledge about their situation determine which bothersome symptom should be managed.

The consensus-based list reflects the recommendations of a small but diverse sample of practicing clinicians and therefore provides only a glimpse into current self-care support recommendations. The list reveals that different clinicians may recommend different self-
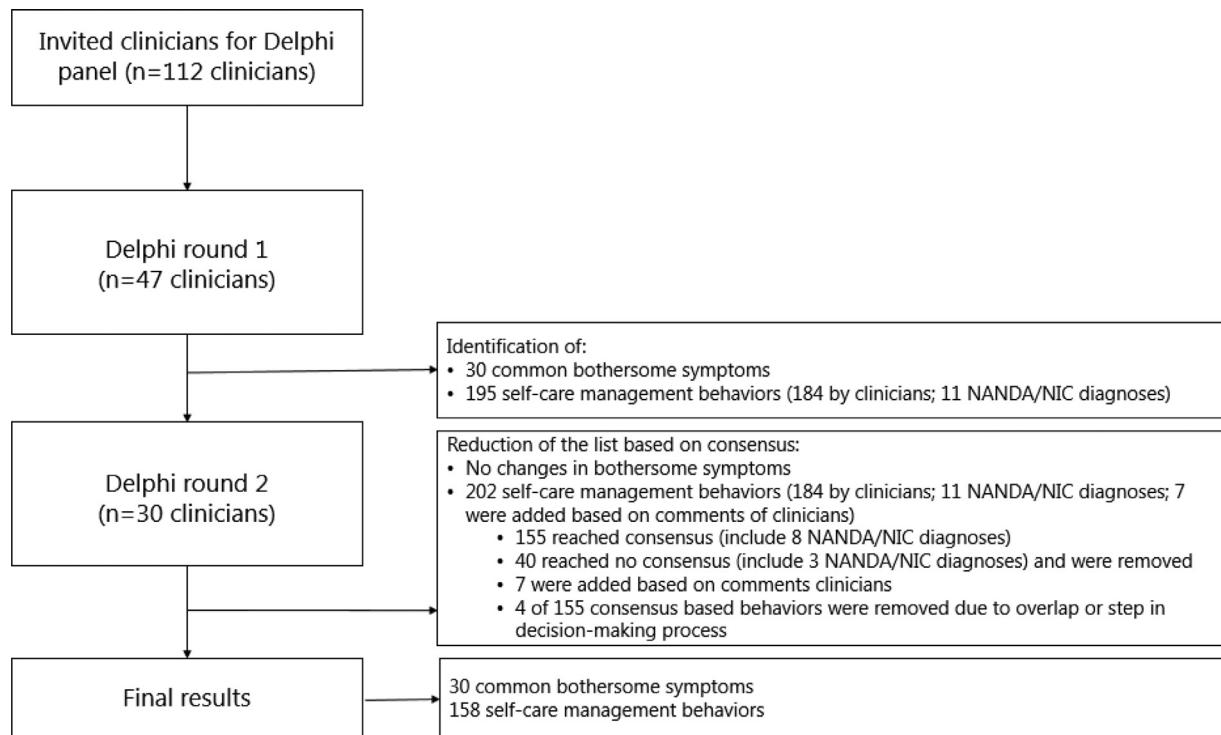
Fig. 2. Results of Delphi round 1 and round 2.

care management behaviors for the same symptom. The list might not be complete, and some of the listed recommendations may not in fact be evidence-based compared with practice guidelines. Although clinicians reached consensus on the vast majority of the recommended behaviors, and although most of the behaviors align with recent guidelines, some of the recommendations are not supported by current evidence. In both Delphi rounds 1 and 2, several self-care management behaviors that are not clearly associated with evidence stand out. For example, in HF, some clinicians listed decreased urine volume/frequency as a bothersome symptom (which is a sign and not a symptom), and almost half of the clinicians agreed to advise patients to rest during the day to increase renal circulation. However, rest might not be relevant advice as renal insufficiency is a prognostic indicator of systolic dysfunction, and the assessment of renal function is essential to adjust medication doses and medical therapy.[20−22] As another example, in DM2, a minority of clinicians recommended the use of sour drinks or ice cubes for hyperglycemia. These recommendations lack evidence and are inconsistent with clinical guidelines.[23,24]

Although we aimed to list bothersome symptoms, clinicians also reported bothersome signs. In clinical practice, most patients with a chronic condition experience both signs and symptoms and report on them interchangeably. If patients indicate discomfort from a sign or a symptom, this requires self-care management recommendations from clinicians.

In an effort to develop an exhaustive list, we added self-care management behaviors between round 1 and 2 that were based on review of the NANDA diagnoses, NIC, and an internet search. Most (8 out of 11) of these added self-care management behaviors reached consensus and were retained in the final list. Postural drainage and chest physiotherapy are nursing interventions to promote airway clearance and were included on patient-focused websites during our internet search; however, they were not agreed upon by the Delphi panel. These discrepancies are consistent with a Global Initiative for Chronic Obstructive Lung Disease report that notes that although self-management intervention programs improve outcomes in COPD,

there is a lack of consensus among what constitutes self-management in COPD.[25,26]

In routine clinical care, the problem of providing recommendations that lack evidence and/or do not comply with clinical guidelines is well-known.[27,28] Underutilization of disease-specific guidelines can be time-related, due to different types of training and expertise, failure to integrate recent guidelines in education, professional group norms, and the challenges of caring for patients with comorbidity.[17,27] Furthermore, adoption of disease-specific guidelines is also influenced by organizational, cultural, and practical factors.[27,28] For example, cultural differences can create discrepancies between clinicians across different countries. In some countries, for example, clinicians advise patients with hypertension to refrain from eating licorice, but in other countries, clinicians do not provide this advice.

Adherence to guidelines is influenced by the clinician's individual mindset, perceptions, and experience. Some may be wedded to what they do and feel comfortable with prior successes, regardless of whether their practices are consistent with current guidelines.[17] In our study, some clinicians commented that they tailor their advice to their patient's preferences or clinical and life situation and/or to the cause of the symptom, which aligns with other studies.[29,30] This implies that some recommendations should be tailored to the patient's individual situation.

The heterogeneity and discrepancies in recommendations that we found can also be explained by the diversity in clinicians as our Delphi panel consisted of registered nurses, nurse practitioners, physicians, and an occupational therapist from four different countries who also differed from one another with respect to education, health care systems, culture, inpatient and outpatient roles. In addition, different national and international guidelines might promote different self-care management behaviors.[31]

Our study focused on the recommendations of clinicians rather than the perspectives of patients. The perception of what is important may differ between clinicians and patients, and clinical

Table 3
Results of Delphi round 1 and 2.

Chronic condition and symptoms	Self-care management behaviors		
	Round 1 Generation of behaviors	Round 2 PA*	Final behaviors**
Heart failure			
Chest pain	Call an ambulance	100%	Call an ambulance
	Take nitroglycerin	94%	Take medication
	Contact healthcare provider	94%	Contact healthcare provider
	Evaluate possible causes	83%	Removed: step in decision making process
	Stop and wait for the pain to pass	72%	Not retained
	Take an aspirin	41%	Not retained
Dizziness	Stand up slowly	100%	Stand up slowly
	Avoid quick movement	94%	Removed: merged with 'Stand up slowly'
	Divide medication doses during the day	86%	Divide medication doses during the day
	Sit and rest	82%	Rest
	Toe lift before standing	71%	Not retained
	Check blood pressure	Com	Check blood pressure
Fatigue/ tiredness	Balance rest & activity	100%	Balance rest & activity
	Divide activities during the day/ take short breaks	100%	Removed: merged with 'Balance rest & activity'
	Plan out activities	94%	Plan out activities and prioritize activities that mean the most
	Take advantage of "good" days and prioritize activity that means the most	89%	Removed: merged with 'Plan out activities and prioritize activities that mean the most'
	Contact health care provider	88%	Contact health care provider
	Check blood pressure	82%	Check blood pressure
	Check pulse	82%	Check pulse
	Engage in as much physical activity as tolerated	72%	Not retained
	Space out medication, adjust dose during the day	67%	Not retained
	Increase nutrition, take supplements	65%	Not retained
	Distract self through doing activities	59%	Not retained
Loss of appetite	Eat small meals	100%	Eat small meals
	Prepare foods that smell and look good	100%	Prepare foods that smell and look good
	Seek advice of a dietician	100%	Seek advice of a dietician
	Eat with other people to make it social	88%	Eat with other people to make it social
	Avoid greasy or fried foods	82%	Avoid greasy or fried foods
	Eat your favorite foods	78%	Eat your favorite foods
Poor sleep quality	Stay physically active	100%	Stay physically active during the day
	Sleep in a dark, quiet room with a comfortable temperature	100%	Sleep in a dark, quiet room with a comfortable temperature
	Avoid caffeine in the evening	94%	Avoid caffeine in the evening
	Limit naps in length	89%	Limit naps in length
	Nap before 3pm	53%	Not retained
Shortness of breath	Check body weight & swelling	100%	Check body weight & swelling
	Call health care provider	100%	Contact health care provider
	Take medication (e.g., diuretic, nitroglycerin)	94%	Take medication
	If worsening, call emergency services/911	94%	Contact emergency services
	Increase number of pillows you sleep with	94%	Increase number of pillows you sleep with
	Use a semi-fowler's position	88%	Use a semi-fowler's position
	Check oxygen saturation & use oxygen if needed	80%	Check oxygen saturation & use oxygen (if applicable)
	Stop activity	78%	Stop activity
	Restrict salt	67%	Not retained
	Reduce fluid	61%	Not retained
Swelling	Take medication (e.g., diuretic)	100%	Take medication
	Check body weight	100%	Check body weight
	Elevate legs	100%	Elevate legs
	Contact health care provider	100%	Contact health care provider
	Measure swelling	94%	Measure swelling
	Use elastic tights	89%	Use elastic tights
	Reduce salt	88%	Reduce salt
	Review diet for hidden sodium	88%	Review diet for hidden sodium
	Reduce liquids	76%	Reduce liquids
Weight gain	Take medication (e.g., diuretic)	100%	Take medication
	Contact health care provider	100%	Contact health care provider
	Check for other symptoms	100%	Check for other symptoms
	Decrease salt	88%	Decrease salt
	Limit fluid	71%	Not retained
Decrease in urine	Contact health care provider	94%	Contact health care provider
	Rest during day to increase renal circulation	41%	Not retained

Table 3 (*Continued*)

Chronic condition and symptoms		Self-care management behaviors		
		Round 1 Generation of behaviors	Round 2 PA*	Final behaviors**
	Shortness of breath while lying down	Call health care provider	100%	Contact health care provider
		Take medication (e.g., diuretic, nitroglycerin)	94%	Take medication
		Use extra pillows at night	94%	Use extra pillows
		Limit fluid and salt	72%	Not retained
	Swollen belly	Check for constipation	94%	Check for obstipation
		Call health care provider	94%	Contact health care provider
		Take medication (e.g., diuretic)	78%	Take medication
		Limit fluid	67%	Not retained
	Thirst	Suck on ice cube	78%	Such on ice cube
		Suck on lemon slices	61%	Not retained
Chronic Obstructive Pulmonary Disease				
	Coughing	Take medication (e.g., inhaler/bronchodilator)	90%	Take medication
		Cough to clear airway	90%	Cough to clear throat/airway
		Reposition to promote effective cough	90%	Reposition to cough more easily
		Contact health care provider	90%	Contact health care provider
		Splint with a pillow when coughing	70%	Not retained
		Hydrate (1.5 L per day)	70%	Not retained
		Postural drainage	50%	Not retained
		Chest physical therapy (e.g., percussion)	50%	Not retained
	Hypoxemia (O2<88%)	Sit upright	100%	Sit upright
		Stop activity	90%	Stop activity
		Cough to clear airway	90%	Cough to clear airway
		Breathing exercises to improve airflow	90%	Breathing exercises to improve airflow
		Increase supplemental oxygen	80%	Increase supplemental oxygen
		Contact health care provider	Com	Contact health care provider
	Loss of appetite	Eat small meals	100%	Eat small meals
		Prepare goods that smell and look good	90%	Prepare goods that smell and look good
		Eat your favorite foods	80%	Eat your favorite foods
		Avoid greasy or fried foods	89%	Avoid greasy or fried foods
		Eat with other people to make it social	80%	Eat with other people to make it social
		Seek advice of a dietician	80%	Seek advice of a dietician
	Shortness of breath	Take medication (e.g., inhaler, steroid)	100%	Take medication
		Assume a tripod position for breathing	100%	Assume a tripod position for breathing
		Do breathing exercises (e.g., pursed lip breathing)	100%	Do breathing exercises (e.g., pursed lip breathing)
		Use oxygen	90%	Check saturation and use oxygen (if applicable)
		Stop activity	90%	Stop activity
		Take slow deep breaths	80%	Take slow deep breaths
		Use a positive expiratory pressure (PEP) device	78%	Use a positive expiratory pressure (PEP) device
	Wheezing	Take medication (e.g., inhaler)	100%	Take medication
		Contact health care provider	Com	Contact health care provider
		Stop or slow down activity	Com	Stop or slow down activity
	Acute shortness of breath	Take medication	100%	Take medication
		Contact health care provider	100%	Contact health care provider
		Call emergency services/911	100%	Contact emergency services
	Fever	Take medication	80%	Take medication
		Stay hydrated	90%	Stay hydrated
	Fatigue/tiredness	Exercise	100%	Engage in as much physical activity as you can
		Adapt activity	90%	Adapt the activity that is less tiring
Asthma				
	Coughing	Take medication (e.g., inhaler)	100%	Take medication
		Deep breathing exercises (slow, deep breaths)	100%	Deep breathing exercises (slow, deep breaths)
		Avoid allergens/triggers	Com	avoid thing that trigger cough
	Fatigue/ tiredness	Engage in as much physical activity as tolerated	100%	Engage in as much physical activity as you can
		Balance rest & activity	88%	Balance rest & activity
		Plan out activities	88%	Plan out activities and prioritize activities that mean the most
		Take medication (e.g., extra bronchodilator dose)	88%	Take medication
		Distract self through doing activities	63%	Not retained

(*continued*)

Table 3 (*Continued*)

Chronic condition and symptoms	Self-care management behaviors		
	Round 1 Generation of behaviors	Round 2 PA*	Final behaviors**
Shortness of breath	Take medication	100%	Take medication
	Assess for triggers (e.g., allergens, environment)	100%	Assess for triggers (e.g., allergens, environment)
	Use relaxation techniques	100%	Use relaxation techniques
	Contact health care provider	100%	Contact health care provider
	Stop activity	88%	Stop activity
	Take slow deep breaths	75%	Take slow deep breaths
	Do breathing exercises (e.g., pursed lip breathing)	75%	Do breathing exercises
	Assume tripod position for breathing	63%	Not retained
Wheezing	Avoid allergens	100%	Avoid things that trigger wheezing
	Take medication (e.g., inhaler)	100%	Take medication
	Seek advice on allergy medication	75%	Seek advice on allergy medication
	Contact health care provider	Com	Contact health care provider
Acute shortness of breath	Take medication	100%	Take medication
	Contact health care provider	100%	Contact health care provider
	Contact emergency services/911	100%	Contact emergency services
	Wear a face mask during cold weather	63%	Not retained
	Stop or slow down activity	Com	Stop or slow down activity
Diabetes mellitus type 2			
Hypergly-cemia Symptom cluster	Check blood sugar	100%	Check Blood Sugar
	Check insulin site (if applicable)	100%	Check insulin site (if applicable)
	Take insulin	100%	Take Insulin
	Drink water	100%	Drink Water
	Modify diet (e.g., fewer fast acting carbs)	93%	Modify diet (e.g., fewer fast acting carbs)
	Call health care provider	93%	Contact health care provider
	Check urine for ketones	87%	Check urine for ketones
	Exercise	87%	Exercise
	Sour or tart drinks	21%	Not retained
	Suck on ice cube	14%	Not retained
Hypogly-cemia Symptom cluster	Check blood glucose	100%	Check Blood glucose
	Eat a fast acting carbohydrate	100%	`Eat a fast acting carbohydrate or glucose tablet/gel
	Recheck blood glucose after eating fast-acting carbs	100%	Recheck blood glucose after eating fast-acting carb/ glucose
	Take glucose tablets/gel	93%	Take glucose tablet/gel
	Adjust insulin dose	93%	Adjust insulin dose
	Call health care provider	93%	Contact health care provider
	Rest	80%	Rest
Diarrhea/ constipation	Call health care provider	93%	Contact health care provider
	Take Metformin with food	73%	Not retained
	Adjust dose of Metformin	73%	Not retained
Fat accumula-tion at insulin injection site	Rotate the injection site	80%	Rotate the injection site
	Use a 4 mm needle	73%	Not retained
Gum problems	Contact dentist	100%	Contact dentist
	Use a fluoride mouth rinse	73%	Not retained
Foot wounds	Keep space between toes dry	100%	Keep space between toes dry
	Contact podiatrist	87%	Contact podiatrist
	Do not get a pedicure until wounds heal	60%	Not retained
Cramps in lower limbs	Wear supportive comfortable footwear	80%	Wear supportive comfortable footwear
	Eat foods rich in Calcium, Potassium, and Magnesium	53%	Not retained
	Rest	47%	Not retained
High blood pressure	Reduce salt intake	100%	Reduce salt intake
	Exercise regularly	100%	Exercise
	Engage in stress relieving activities	80%	Do stress relieving activities
	Adjust medication	73%	Not retained
Sensitivity to touch and vibration	Exercise	87%	Exercise
	Take medication (e.g., NSAID, Capsaicin Cream)	33%	Not retained
	Supplement Vitamin D with sunlight or pill	60%	Not retained
	Supplement Vitamin B Complex	60%	Not retained
	Soak in a warm bath	67%	Not retained
Arthritis			
Fatigue/ tiredness	Balance rest & activity	100%	Balance rest & activity
	Engage in as much physical activity as tolerated	100%	Engage in as much physical activity as you can
	Distract self through doing activities	100%	Distract self through doing activities
	Plan out activities	100%	Plan out activities and prioritize activities that mean the most

Table 3 (*Continued*)

Chronic condition and symptoms	Self-care management behaviors		
	Round 1 Generation of behaviors	Round 2 PA*	Final behaviors**
Joint pain	Take medication	100%	Take medication
	Physical activity	100%	Physical activity
	Rest	100%	Rest
	Distract self through doing activities	100%	Distract self through doing activities
	Use a disability aid	100%	Use a disability aid
	Stretch	75%	Stretch
	Water therapy	75%	Water therapy
	Apply cold	75%	Apply cold
	Elevate the affected joint	75%	Elevate the painful joint
	Apply heat	50%	Not retained
	Contact health care provider	50%	Not retained
	Massage	25%	Not retained
Joint stiffness	Apply heat	100%	Apply heat
	Water therapy/pool therapy	100%	Water therapy/pool therapy
	Take a warm shower	100%	Take a warm shower
	Physical activity	100%	Physical activity
Joint swelling, redness, and/or warmth	Rest	100%	Rest
	Apply cool	100%	Apply cool
	Contact health care provider	100%	Contact health care provider
	Take medication	75%	Take medication
	Elevate the affected joint	75%	Elevate the joint
Physical limitation/activity limitation	Adapt the activity	100%	Adapt the activity
	Seek assistance	100%	Seek help completing the activity
	Use disability aid	100%	Use disability aid (for example, cane or walker)
	Range of motion exercises	100%	Do range of motion exercises
	Rest	100%	Rest
	Contact health care provider	50%	Not retained

*items with <75% agreement were removed; **analyzed by the research team.
Abbreviations: Com, comments of clinicians; PA, percent agreement.

Table 4
Meaningful comments of clinicians of Delphi round 1 and 2.

Topics	Results	Citations from clinicians
Tailoring recommended behavior to the cause of the symptom, patients' situation and clinicians' preference	Clinicians often commented that their decision to advise specific behaviors depends on the cause of the symptoms and need to be tailored to the situation of the patient. They first try to find out what causes the symptom and tailor their advice to the patients' situation. Decision-making also depends on the expertise and preference of clinicians.	*"It is usually not one or the other. It can be multiple things at once [...]. It depends on the person and situation". [Arthritis]* *"I would rather teach patients that hypoglycemia is a serious complication of treating diabetes, which should be avoided". [DM2]* *"the advices are formulated as black and white, but take extra diuretics only after this has been agreed, not to be applied by everyone". [HF]*
Discrepancies in recommended behaviors	Some clinicians commented on the content of their advised behaviors. Comments generally aligned between the clinicians. However, some discrepancies were found in the comments regarding behaviors to checking blood sugar after hypoglycemia, e.g., taking sugar and/or drinking milk and eat a sandwich. Some advice might be cultural specific, e.g., eating liquorice is common in the Netherlands and is known for increasing the blood pressure.	*"Take a sachet of sugar (15 g) and re-check the blood glucose after 15 min. Repeat the procedure until blood glucose gets normal." [DM2]* *"Drink milk and eat a sandwich." [DM2]* *"Do not eat liquorice." [HF]*

advice should be tailored to the needs and preferences of patients.[32] Further research is needed to determine whether patients agree with clinicians as to which symptoms are bothersome and as to whether they view the behaviors that clinicians recommend as being both helpful and feasible. Furthermore, we know that clinicians consistently acknowledge the importance of focusing on knowledge and emphasize patient education rather than behavioral strategies to improve self-care management behaviors.[29] How and to what extent clinicians discuss their recommendations with patients and whether patients comply with these recommendations when experiencing bothersome symptoms needs further research.

Strengths and limitations

A strength of this study was the variety of clinicians in our expert panel. Nurses, nurse practitioners, an occupational therapist, and physicians of four different countries agreed on bothersome symptoms and self-care behaviors, which promotes the generalizability of these results in routine care across borders.

This study also has some limitations. First, despite extensive recruitment from the network of the researchers and snowball sampling with multiple reminders, the response rate was not high in either round. Our study was conducted during the Covid-19 pandemic, which might explain why some clinicians were unable to

participate. Due to the low response rate, we did not meet our cut-off point of including 15 clinicians per chronic condition for arthritis (n = 6) and asthma (n = 12). This could mean that, for these conditions, some bothersome symptoms and self-care behaviors may have been overlooked. Second, as the vast majority of the clinicians had a nursing background, the results of our study mainly reflect nurses' recommendations and consensus of bothersome symptoms and self-care management behaviors. However, in clinical practice, most of the recommendations regarding self-care management are done by nurses. Third, given the wide variety in the methodological designs of Delphi studies, little foundation for our methodological decisions can be provided. However, we followed a commonly used research guideline for Delphi studies.[11] Prior to starting the study, we decided that two Delphi rounds should be sufficient,[11,12] but additional rounds might have led to the identification of additional bothersome symptoms and self-care management behaviors. Also, the Delphi rounds consisted of surveys rather than face-to-face meetings, which did not allow us to discuss ratings, discrepancies, and rationales for clinicians' opinions. However, clinicians were invited to comment on their ratings, and we were able to include almost 50 clinicians in our expert panel.

Conclusions

A total of 30 bothersome symptoms and 158 self-care management behaviors of HF, COPD, asthma, DM2, and arthritis that can reduce symptom impact were identified by an international panel of clinicians. There was consensus among the clinicians on many points but also some disagreements and a few of the recommendations are inconsistent with current guidelines.

Further research and effective implementation strategies are needed to encourage more clinicians to recommend effective self-care management behaviors to reduce the impact of common bothersome symptoms of major chronic conditions.

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