Symptom characteristics, perceived causal attributions, and contextual factors influencing self-care behaviors: An ecological daily assessment study of adults with chronic illness☆

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ABSTRACT

Objective: Insights into how symptoms influence self-care can guide patient education and improve symptom control. This study examined symptom characteristics, causal attributions, and contextual factors influencing self-care of adults with arthritis, asthma, chronic obstructive pulmonary disease, diabetes, or heart failure.

Methods: Adults (n = 81) with a symptomatic chronic illness participated in a longitudinal observational study. Using Ecological Daily Assessment, participants described one symptom twice daily for two weeks, rating its frequency, severity, bothersomeness, duration, causes, and self-care.

Results: The most frequent symptoms were fatigue and shortness of breath. Pain, fatigue, and joint stiffness were the most severe and bothersome. Most participants engaged in active self-care, but those with fatigue and pain engaged in passive self-care (i.e., rest or do nothing), especially when symptoms were infrequent, mild, somewhat bothersome, and fleeting. In people using passive self-care, thoughts, feelings, and the desire to conceal symptoms from others interfered with self-care.

Conclusion: Most adults with a chronic illness take an active role in managing their symptoms but some conceal or ignore symptoms until the frequency, severity, bothersomeness, or duration increases.

Practice implications: When patients report symptoms, asking about self-care behaviors may reveal inaction or ineffective approaches. A discussion of active self-care options may improve symptom control.

1. Introduction

The number of individuals suffering from one or multiple chronic illnesses (e.g., heart disease, diabetes) is increasing worldwide [1]. Treatments are available for these conditions, but there are currently few cures, leaving many people with frequent and bothersome symptoms over a long period of their lives. Symptoms are closely linked to the decisions that patients with a chronic illness make about interpreting and responding to their illness [2,3]. Understanding the processes involved in these illness behaviors is essential for effective patient

education. The purpose of this study was to describe how symptom characteristics vary over time, and to identify how these characteristics and self-care decision-making styles influence the self-care management behaviors of adults with chronic illness. An innovative feature of this study was a focus was on symptoms rather than specific chronic conditions. This approach is consistent with the views of patients who consider illness representation profiles rather than specific diseases [4].

According to the theory of self-care of chronic illness [5], health is maintained through a process of health-promoting practices and illness management behaviors. The decision to initiate self-care management behaviors (e.g., take medication, seek advice) is usually preceded by a symptom, defined as a subjective physical or mental experience reflecting a bodily change [2]. Recognizing a change and labeling it as a symptom depends on one's appraisal of symptom characteristics (e.g., severity, bothersomeness) [6], but personal (e.g., multimorbidity, causal attribution), and environmental (e.g., social support) factors can influence the detection and interpretation of a symptom [7–9]. As such, symptoms act as conscious signals to protect us from bodily threat by stimulating action [10].

Intensity, interference, and frequency are important dimensions of the symptom experience [11]. Temporal elements of these dimensions are important influences on interpretation and have not been widely studied. Not only do symptoms change over time as a disease progresses or remits, but in some conditions, there are notable symptom variations within and between days. In adults with heart failure (HF) [12] and those with chronic obstructive pulmonary disease (COPD) [13], symptom variability is common and acknowledged as an indicator of an acute exacerbation [14]. In COPD, symptoms show high seasonal, weekly, and even daily variability with increases in symptom burden in the morning [15,16]. Symptoms with a rapid, acute onset are typically more worrisome to patients than slowly evolving symptoms [17]. In HF, an acute change in symptoms may signal an impending hospital admission [18]. HF symptoms that fluctuate predict shorter event-free survival after adjusting for symptom severity, clinical and demographic characteristics [19].

A large body of research addresses symptoms, and a separate body of evidence addresses self-care. However, relatively little is known about the self-care behaviors used by patients who experience symptoms [2]. Identification of factors that influence self-care decisions in response to symptoms can guide the development of more effective educational strategies, and in turn help patients to engage in better self-care management and have better symptom control. With this goal in mind, the specific aims of this study were to (i) describe symptom characteristics, perceived causal attributions, and contextual factors such as time stress and input from others, (ii) track symptom variability over time, and (iii) describe how these factors influence the self-care behaviors of adults with arthritis, asthma, COPD, diabetes, and/or HF.

2. Methods

We conducted a longitudinal observational study, obtaining twice-daily measurements from a convenience sample of adults with a symptomatic chronic medical condition over a two-week period. We planned to recruit 400 participants, with 20 per chronic condition and 100 per country (Italy, the Netherlands (NL), Sweden, and the United States (USA)) https://doi.org/10.17605/OSF.IO/8473 K. After statistical power was recalculated based on observations rather than enrolled individuals, power for the major analyses was found to be adequate with a total of > 1000 observations. If every participant were to provide all 28 observations, a sample size of 36 would be needed to accrue a total of at least 1000 observations. To allow for attrition, we recruited more than 36 participants.

Knowing that self-care management behaviors are influenced by cultural norms [3], we collected data in four countries after performing a Delphi survey of clinician recommendations for self-care in these countries [20]. Individuals were eligible for inclusion if they reported ≥

3 months of experience with arthritis, asthma, COPD, diabetes, and/or HF and were currently experiencing bothersome symptom(s). Chest pain, coughing, dizziness, fatigue, symptoms of high or low blood sugar, joint stiffness, joint swelling/redness/warmth, loss of appetite, pain, shortness of breath, swelling, or wheezing had to be experienced at least three times weekly for the individual to be eligible for inclusion. Participants had to own a smartphone with an adequate data plan or home Wi-Fi to enable app use and be sufficiently technically adept to use the app for data collection. They had to be fluent in the language of the country where data were collected (Italian, Dutch, Swedish, or English) and ≥ 18 years of age.

Exclusion criteria were living in a setting or situation where self-care cannot be performed independently (e.g., nursing home), and cognitive impairment that makes answering questions difficult. All recruitment was done electronically through social media, defined as websites or mobile apps where users can create and share information and build virtual communities[21].

2.1. Data collection procedure

The study was approved by the University of Pennsylvania Institutional Review Board in the USA after expedited review. Participants resided in four different countries, but enrollment and data collection took place only at the University of Pennsylvania. Collaborating institutions in the different countries allowed co-investigators from Italy, NL, and Sweden to recruit participants locally. A simplified consent on the first page of the survey accommodated both the Health Insurance Portability and Accountability (HIPAA) law in the USA and the General Data Protection Regulation (GDPR) in Europe.

Research staff enrolled participants in their respective countries using social media. Recruitment methods directed interested individuals to a REDCap (Research Electronic Data Capture) survey form to review the study information and complete eligibility screening questions. Eligible adults who provided informed consent completed baseline measures on REDCap, day 0. Those who passed the data quality check were then invited to download a mobile phone app, RealLife Exp (LifeData © 2021 LifeData, LLC), and complete two weeks of data collection using Ecological Daily Assessment (EDA) [22]. EDA is a variant of Ecological Momentary Assessment and is used to measure self-reported data in real time in the participant's natural environment. This real-time capture of self-report data was used to minimize the recall biases that can diminish the reliability and validity of retrospective self-reports [23].

At the start of the 2-week period, participants selected their most frequent and bothersome symptom from a list of 13 symptoms and reported on that symptom for the entire period (Fig. 1). With each prompt, participants were asked whether their chosen symptom had occurred since the previous prompt. If yes, they were asked about symptom characteristics and causes. They were presented with a symptom-specific list of self-care management behaviors as well as options of "other" [free text] and "none." Then they chose among several options for why they chose that action. If they did not have the symptom, they could report on a different symptom, what they did about the symptom, and why they chose that action. Participants were compensated for their time.

2.2. Measurement

2.2.1. Symptoms

We were interested in symptoms as a momentary state or an experience that fluctuates over time [24]. Since we enrolled patients with different illnesses, we did not use scales measuring symptoms caused by specific illnesses (e.g., HF) [25]. Instead, we chose relevant symptoms from a list of 30 symptoms generated by a two-round Delphi survey of an international panel of clinicians [20]. Symptom frequency was classified as occurring once per day, several times per day, or constantly. Severity
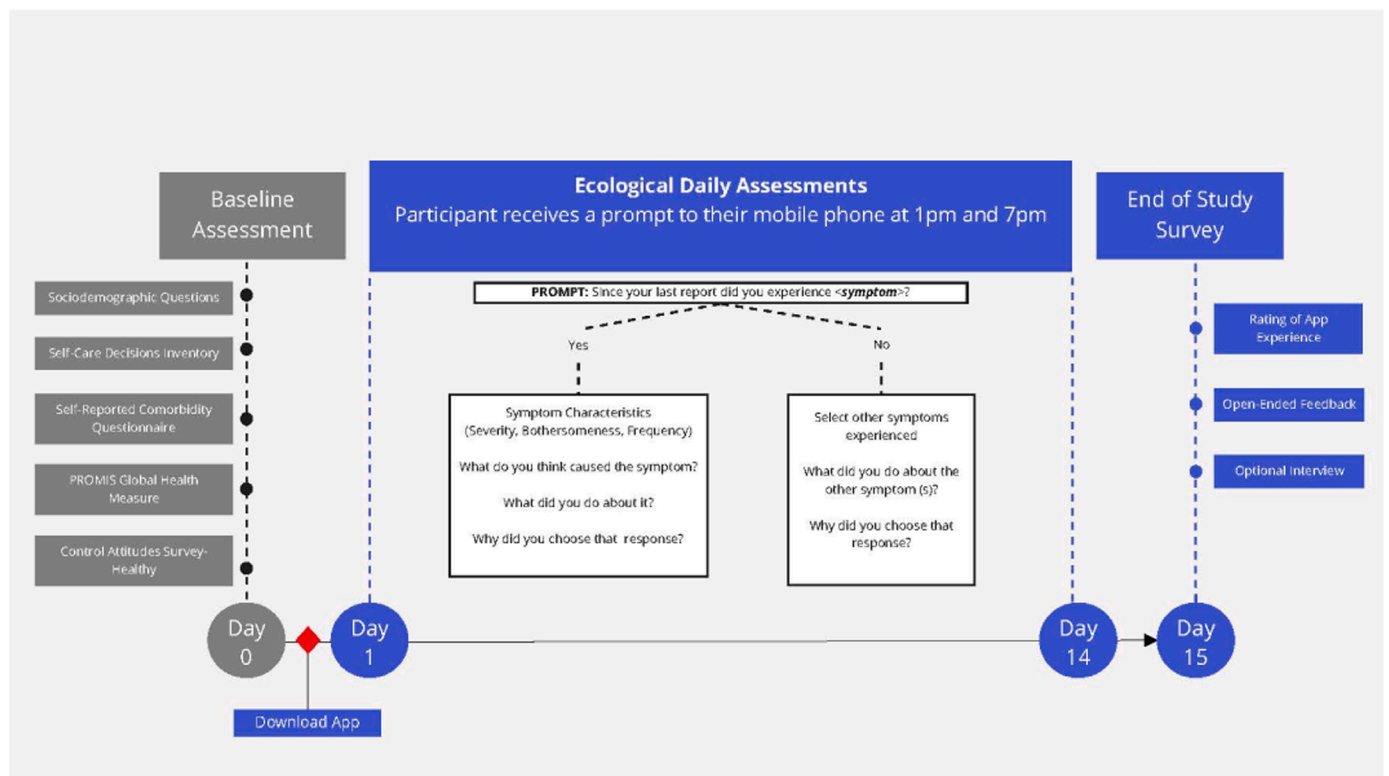
Fig. 1. This flowchart displays the data collection procedure. Participants completed a baseline assessment on day 0 then downloaded a mobile phone app and completed twice daily ecological daily assessments on days 1–14. A survey was administered on day 15. Procedures in grey were completed on REDCap and procedures in blue were completed on the LifeData RealLife Exp mobile phone app.

was rated as mild, moderate, somewhat severe, or severe. Bothersomeness was rated on a four-point scale from 'not at all' to 'very' bothersome. Variability was calculated for each person based on the variance reported in severity and bothersomeness over time. Symptom causes were categorized as a change in their chronic condition(s), their behavior, mood, stress, environment, the food eaten, something else, or unknown.

2.2.2. Self-care management behaviors

Self-care management behaviors performed in response to a symptom (e.g., take medication), were assessed each time a symptom was reported, with response options selected from our Delphi survey [20]. For symptoms that occur in multiple conditions (e.g., shortness of breath, fatigue), we combined lists of self-care management behaviors so that the response options were symptom-specific, not condition-specific. Participants could select all self-care management behaviors performed, provide free text if they did something else, or indicate that they did nothing. Behavioral responses were categorized independently by two self-care experts as passive (i.e., rest or do nothing) or active (e.g., take medication). A third team member adjudicated when there was disagreement between the two experts.

2.2.3. Contextual factors influencing self-care decisions

At enrollment participants completed the Self-Care Decisions Inventory, a 27-item self-report instrument measuring the extent to which contextual factors such as time stress and input from others influence decisions about symptoms of chronic illness [26]. Six scale scores are calculated. *External* is the extent to which input from other people influences self-care decisions. *Urgency* is the extent to which perceived urgency or high stakes influence decisions. *Uncertainty* is the extent to which uncertainty or ambiguity influence decisions. *Cognitive/affective* reflects the extent to which thoughts or feelings influence decisions. *Waiting/cue competition* is the extent to which situational factors delay

decision making. Finally, *concealment* reflects the extent to which a desire to hide symptoms from others influences decisions. Higher scores on each scale indicate that the factor has greater influence on self-care decisions.

2.2.4. Sociodemographic factors

Sociodemographic factors assessed at baseline included the respondent's country of residence, age, gender, education, employment, and perceived adequacy of financial income. Due to differences in research practices across countries, we assessed race and ethnicity in the USA participants only.

2.3. Data analysis

Descriptive statistics were used to summarize patterns of symptom frequency, bothersomeness, severity, duration, and variability across the 28 EDA measurements per participant, participants' beliefs about the causes of symptoms, the use of self-care management behaviors performed in response to specific symptoms, and contextual factors influencing decisions about self-care. Symptom frequency was derived from the number of EDA responses provided for 14 days. Symptom bothersomeness, severity, and duration were obtained by averaging the ratings across measurements obtained for each participant. To quantify symptom variability, we calculated within-person variance based on each participant's EDA responses. This was done separately for severity, bothersomeness, and duration. Then, to obtain overall variability, we calculated the variance from the available number of responses. This was done for the overall sample and repeated for each symptom, reporting the within-subject and between-subject variance. We fit binary logistic regression models to the data under the Generalized Estimating Equation (GEE) framework to account for interdependencies among repeated measures within each participant, and calculated odds ratios (and 95% confidence intervals and p-values) of engaging in passive self-

care management. We used a mixed-effects binary regression model with random intercept to calculate the intra-class correlation of EDA responses [36]. Chi square and t-tests, where appropriate, were used to compare contextual factors at baseline influencing self-care management behaviors. Bonferroni adjustment was used to minimize the risk of Type 1 errors over multiple comparisons.

3. Results

A total of 173 respondents were eligible and consented to participate in the study; however, 27 did not complete the baseline assessment and 19 were excluded due to data quality concerns (Fig. 2). Thus, 127 participants were invited to participate in the two weeks of EDA and 81 downloaded the RealLife Exp app (64% enrollment rate). Of these, 1 dropped out immediately and 4 others selected symptoms to report on (1 pain, 1 low blood sugar, 1 shortness of breath, 1 fatigue) but never responded to any EDA prompts. Thus, EDA data were obtained from 76 participants (94% completion rate). The 76 active participants received a total of 2103 EDA prompts. Participants responded to prompts on 1801 out of 2103 occasions. In 20 instances they did not complete the session, so the effective response was 1781 (85% response rate). Participants reported that their selected symptom was present in most instances;

however, on 580 occasions (27% of the time), participants responded that they did not experience their selected symptom since their last report. Thus, 1201 responses were used in analyses that depended on symptom occurrences.

3.1. Characteristics of the sample

On average, participants were middle-aged, female, and well-educated (Table 1). Half of them were employed, 20% were retired, and 20% were unable to work due to illness or disability. Few reported financial concerns. The most common conditions were asthma and diabetes mellitus. Most participants lived in Europe.

3.2. Characteristics of symptoms

Asthma was the condition associated with the most symptoms (Table 2). Fatigue and shortness of breath were the most prevalent symptoms, reported by 22 participants each (Table 3). Average estimates and variability in symptom bothersomeness and severity are shown in Table 4. Participants reported greater bothersomeness than severity for most symptoms. There was also greater variability in the bothersomeness of most symptoms, compared with variability in
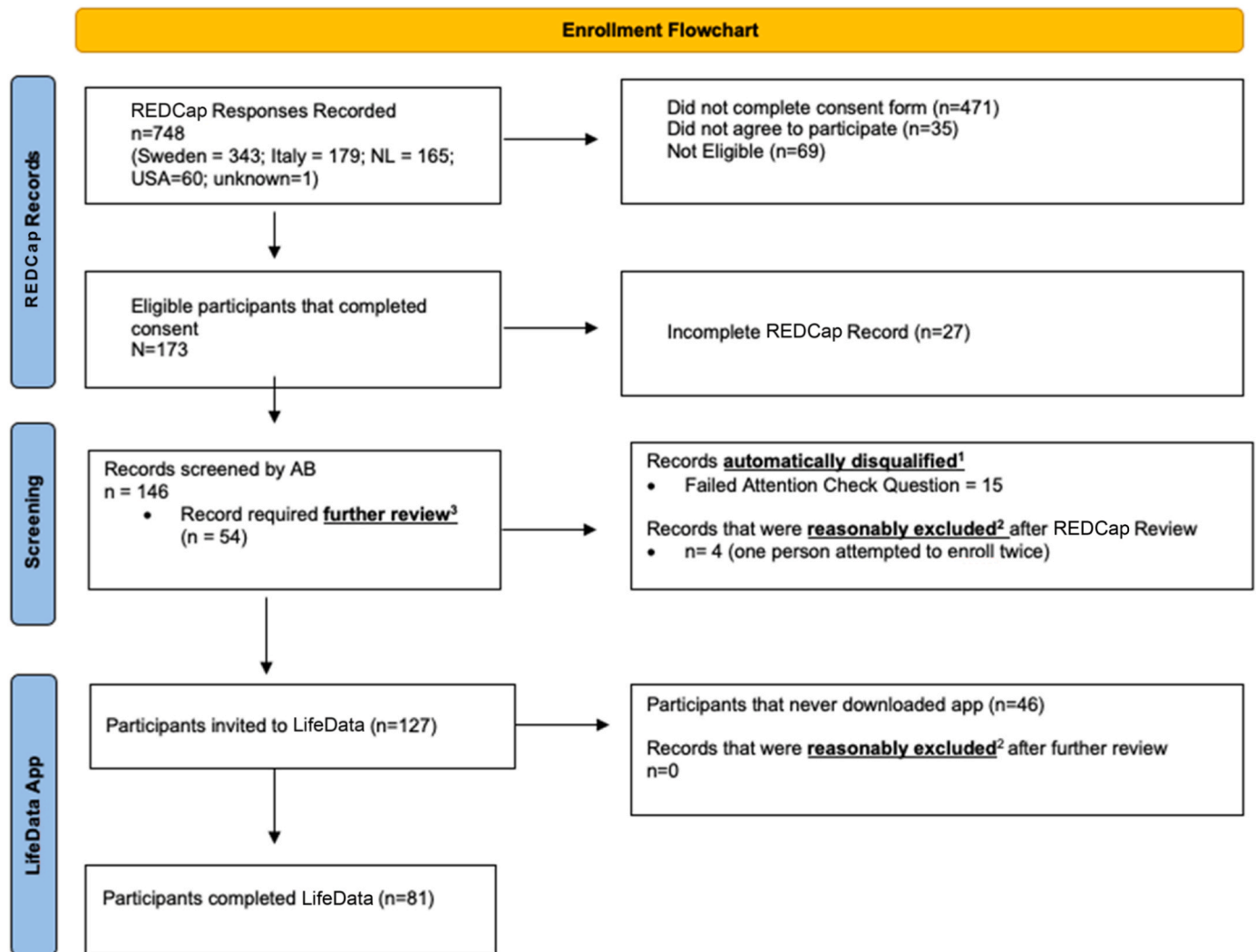
Fig. 2. Enrollment flowchart. This flowchart displays the process of enrollment from viewing the consent form in REDCap to completing two weeks of EDA. Participants were invited to complete Life Data and the EDA responses were reviewed for data quality.
Key: 1 = Automatically Disqualified; participant had one or more red flags. 2 = Reasonably Excluded; participant had (i) 2 or more orange flags or (ii) 4 or more flags, one of which was orange. 3 = Further Review; participant did not meet criteria for automatic disqualification or reasonable exclusion.

Table 1
Participant characteristics (n = 81).

Variable	*n* (%)
Age	48.5 (15.2)
Mean (SD)	20–80
Minimum-Maximum	
Gender	
Female	62 (76.5)
Male	18 (22.2)
Prefer Not to Answer	1 (1.3)
Country	25 (30.9)
The Netherlands	24 (29.6)
Sweden	22 (27.2)
Italy	10 (12.3)
United States of America	
Condition*	16 (19.8)
Arthritis	35 (43.2)
Asthma	12 (14.8)
COPD	26 (32)
Diabetes Mellitus	11 (13.6)
Heart Failure	
Education	
Less than High School	5 (6.2)
High School Diploma or Equivalent	24 (29.6)
College Degree (Associate's or Bachelor's)	36 (44.4)
Graduate Degree (Master's or Doctoral)	15 (18.5)
Other	1 (1.3)
Employment	
Student or Trainee	3 (3.7)
Full Time	24 (29.6)
Part Time	17 (21)
Unemployed	3 (3.7)
Unable to work due to illness/disability	16 (19.8)
Retired	16 (19.8)
Other	2 (2.5)
Finances	
Have enough to make ends meet	60 (74.1)
Do not have enough to make ends meet	6 (7.4)
Have more than enough to make ends meet	15 (18.5)
Race *(n = 10)*	
White	7 (70)
Black	2 (20)
Native American/Alaska Native	1 (10)
Ethnicity *(n = 10)*	
Non-Hispanic	10 (100)

* Participants could select more than 1 condition

symptom severity. However, variability in the severity of fatigue and wheezing were greater than the variability in bothersomeness for these symptoms. There was equivalent variability in the bothersomeness and severity of shortness of breath (Fig. 3). Pain was the most bothersome and severe symptom overall, joint stiffness was the most variable in bothersomeness, and fatigue was the most variable in severity over time (Fig. 4). Wheezing also was highly variable but only two participants reported on wheezing.

Causal Attributions: Of the 22 subjects reporting twice daily on fatigue, changes in stress (38%) and the environment (47%) were most often reported as the likely causes. Another 22 subjects provided twice daily assessments on shortness of breath. When asked about the cause of their shortness of breath, approximately one-third endorsed a change in the environment. Across all conditions and all levels of bothersomeness, the responses chosen most often were a change in the environment

(26%), stress (23%), the chronic condition (21%), my behavior (20%), and unknown (23%). Note that participants could select numerous causes, so the sum was greater than 100%.

3.3. Self-care management in relation to symptom characteristics and contextual factors

The frequency of the self-care management techniques used for each symptom is shown in Table 5. Only 10 (13.2%) respondents relied primarily on passive self-care management approaches while 66 (86.8%) used active self-care behaviors most of the time. Those reporting on shortness of breath, cough, and wheezing engaged in mostly active behaviors, whereas those reporting on fatigue and pain engaged in primarily passive behaviors. The day-to-day variability of passive and active behaviors was consistent much of the time (Fig. 5). When we compared participants using active and passive behaviors, there were no statistically significant differences in any of the descriptive characteristics (p > 0.05).

The mixed-effects regression model yielded an ICC of 0.54 which indicates that about 54% of observed variability in the EDA responses can be attributed to participants. When we used GEE modeling to evaluate the association between symptom characteristics and self-care management behavior, we found statistically significant associations with all four symptom characteristics (symptom frequency, severity, bothersomeness, and duration) and self-care management behavior (Table 6). Participants most likely to use passive self-care strategies were those reporting infrequent and mild symptoms that were only somewhat bothersome and lasted only an hour or less.

Differences were also identified in contextual factors influencing self-care management behaviors. Participants using primarily passive self-care approaches had greater influences from cognitive/affective issues (45.6 ± 23.8 vs. 32.2 ± 15.1, p = 0.04) and the desire to conceal symptoms from others (63.3 ± 27.8 vs. 37.8 ± 21.0, p < 0.01) compared to those using primarily active self-care behaviors.

Table 3
Frequency of EDA prompts and response.

Symptom	Number of Subjects	Number of Responses (Total possible prompts)	Number of prompts when symptom is said to be absent
Fatigue	22	473 (616)	169
Shortness of Breath	22	506 (616)	124
Pain	9	195 (252)	26
Low Blood Sugar	8	184 (224)	114
High Blood Sugar	7	168 (196)	78
Joint Stiffness	5	100 (140)	24
Cough	4	112 (112)	14
Wheezing	2	53 (56)	27
Loss of Appetite	1	10 (28)	4

Note: A total of 2103 prompts were sent.

Table 2
Frequency of symptom reporting by chronic condition.

Condition	Cough	Fatigue	High Blood Sugar	Joint Stiffness	Loss of Appetite	Low Blood Sugar	Pain	Shortness of Breath	Wheezing	Total
Arthritis	0	4	0	5	0	1	6	0	0	16
Asthma	3	9	0	0	0	0	3	18	2	35
COPD	1	2	0	0	0	0	2	7	0	12
Diabetes Mellitus	0	4	7	1	0	8	4	2	0	26
Heart Failure	0	6	1	0	1	0	1	0	0	10

Key: COPD = chronic obstructive pulmonary disease

Table 4
Average and Variability in Symptom Bothersomeness and Severity.

Symptoms	Average Bothersomeness	Variability in Bothersomeness	Average Severity	Variability in Severity
Fatigue (n = 22)	2.44 ± 0.60	0.55 ± 0.25	2.12 ± 0.47	0.60 ± 0.17
Shortness of Breath (n = 22)	2.38 ± 0.58	0.55 ± 0.29	1.94 ± 0.52	0.55 ± 0.28
Pain (n = 9)	2.59 ± 0.66	0.55 ± 0.09	2.23 ± 0.79	0.53 ± 0.16
Low Blood Sugar (n = 8)	1.85 ± 0.47	0.58 ± 0.16	1.41 ± 0.37	0.45 ± 0.35
High Blood Sugar (n = 7)	1.86 ± 0.35	0.64 ± 0.25	1.72 ± 0.24	0.59 ± 0.33
Joint Stiffness (n = 5)	2.43 ± 0.48	0.69 ± 0.26	2.11 ± 0.37	0.42 ± 0.32
Cough (n = 4)	1.74 ± 0.77	0.46 ± 0.11	1.69 ± 0.81	0.40 ± 0.10
Wheezing (n = 2)	2.21 ± .21	0.65 ± 0.21	1.71 ± 0.53	0.78 ± 0.08
Loss of Appetite (n = 1)	1.5	0.54	1.33	0.51

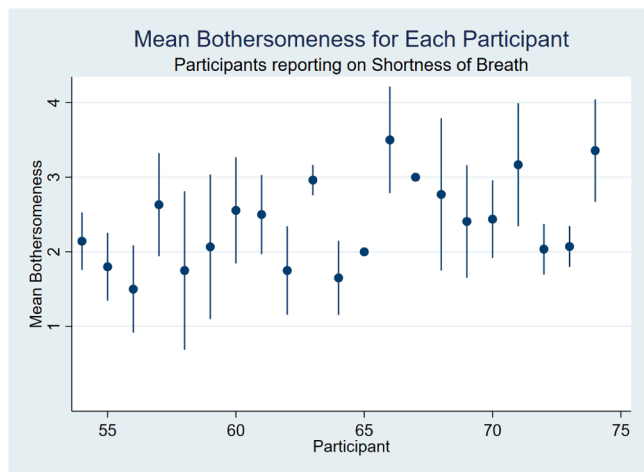Results reported in Mean ± Standard Deviation

Fig. 3. Mean bothersomeness of shortness of breath over the two-week period.
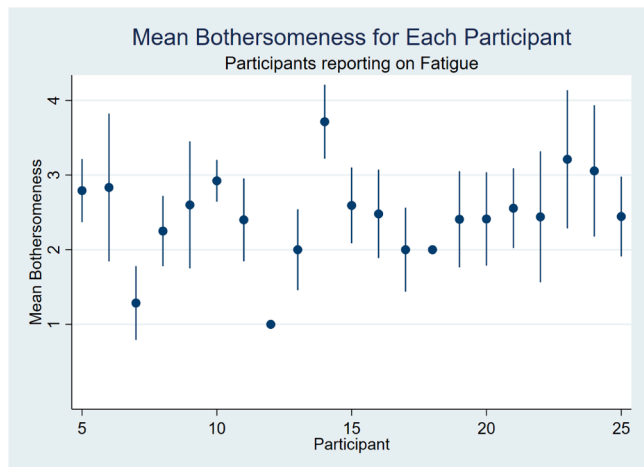

Fig. 4. Mean bothersomeness of fatigue over the two-week period.

Table 5
Frequency of Self-Care Management Technique Used for the Various Symptoms.

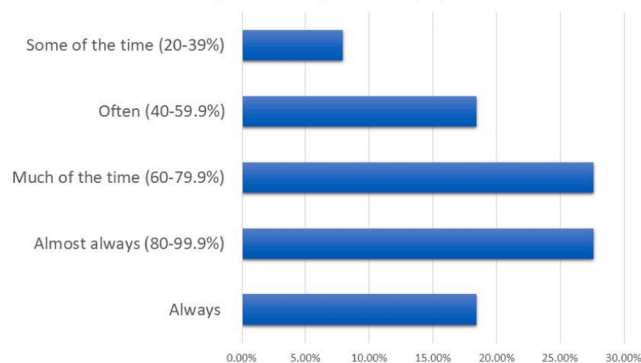| Symptom	Active	Passive
Cough	89	9
Fatigue	211	88
High Blood Sugar	85	0
Joint Stiffness	50	23
Loss of Appetite	1	5
Low Blood Sugar	67	1
Pain	142	25
Shortness of Breath	349	25
Wheezing	21	5

Fig. 5. Percentage of time participants used the same self-care management response to symptoms.

4. Discussion and conclusion

4.1. Summary of main findings

Patient education often focuses on increasing understanding of symptoms so as to support and prompt self-care behaviors such as symptom monitoring and management [27]. In this study we sought to identify symptom characteristics, perceived causal attributions, and contextual factors that influence self-care by adults with chronic illness. A novel element of this study was our focus on symptoms rather than specific chronic conditions. Another novelty was that it linked symptoms to self-care responses. We found that self-care behaviors differ among adults with chronic illness depending on symptom characteristics and contextual factors. Previous studies have shown that symptoms or changes in symptoms influence decisions, but this is the first study to examine the factors influencing self-care across a range of symptoms. Pain, fatigue, and joint stiffness were most severe and most bothersome, and these symptoms were present much of the time. Because our focus was on symptoms, we also were able to provide novel insight on several symptom characteristics over time: pain was the most bothersome and severe symptom overall, joint stiffness was the most variable in bothersomeness, and fatigue was the most variable in severity. Our findings show that patients tend to wait until their symptoms are frequent, severe, bothersome, and/or persistent before engaging in active symptom management. Those using passive self-care are more likely to endorse the influence of thoughts, feelings, and the desire to conceal symptoms from others [28].

At first glance, the severity and bothersomeness of symptoms seem to be explained by the underlying diagnosis (lung disease or arthritis); however, fatigue and pain are common across many chronic conditions. For example, pain is reported frequently in HF [29] and COPD [30,31]. In our study, participants did not attribute their symptoms to changes in the chronic condition or their behavior but instead they attributed fatigue to stress and the environment and attributed shortness of breath

Table 6

Odds of Using a Passive Self-Care Management Technique by Symptom Frequency, Bothersomeness, Severity and Duration.

Symptom Characteristics	Pairwise Comparison	Odds Ratio	Bonferroni corrected 95% CI
Symptom Frequency	Once vs. Several Times	1.80	1.11, 2.90 *
	Once vs. Symptom is Constant	1.82	0.88, 3.75
	Several Times vs. Symptom is Constant	1.01	0.51, 1.99
Symptom Severity	Mild vs. Moderate	2.75	1.36, 5.56 *
	Mild vs. Somewhat Severe	3.22	1.47, 7.08 *
	Mild vs. Severe	1.44	0.53, 3.93
	Moderate vs. Somewhat Severe	1.17	0.64, 2.13
	Moderate vs. Severe	0.52	0.23, 1.20
	Somewhat Severe vs. Severe	0.45	0.16, 1.29
Symptom Bothersomeness	Not at all bothersome vs. Somewhat Bothersome	0.25	0.10, 0.61 *
	Not at all bothersome vs. Bothersome	0.88	0.50, 1.56
	Not at all bothersome vs. Very Bothersome	1.11	0.41, 3.04
	Somewhat Bothersome vs. Bothersome	3.48	1.71, 7.08 *
	Somewhat Bothersome vs. Very Bothersome	4.40	1.44, 13.41 *
	Bothersome vs. Very Bothersome	1.26	0.49, 3.26
Symptom Duration	A few minutes vs Several minutes to an hour	2.31	1.10, 4.85 *
	A few minutes vs. A few hours	3.26	1.22, 8.71 *
	A few minutes vs. It never went away	1.67	0.44, 6.27
	Several minutes to an hour vs A few hours	1.41	0.71, 2.78
	Several minutes to an hour vs. It never went away	0.72	0.20, 2.64
	A few hours vs. It never went away	0.51	0.13, 2.05

*Indicates a significant association after adjusting for multiple comparison using Bonferroni approach.

primarily to the environment. These symptom attributions underline the importance of asking patients not only about the symptoms they experience, but also querying them about factors they perceive as triggering their symptoms. Learning about factors that trigger symptoms is an important step in developing strategies to ameliorate them before they become more severe or bothersome.

Previous studies have described symptom management strategies as being passive or active; [32] however, in our study we went further to link these behavior patterns to certain symptoms, symptom characteristics, and contextual influences. Passive self-care management behaviors were often reported by participants with fatigue and pain. Those with infrequent and mild symptoms that were not very bothersome or persistent in duration engaged in more passive behaviors, such as doing nothing. Yet, self-care management approaches for fatigue are found in the literature [33] and the early treatment of pain has been advocated for years [34] with the goal of preventing an escalation of frequency, severity, bothersome, and duration. Passive self-care management behaviors in response to symptoms that are treatable underline the complexity of how symptom characteristics influence the decisions about self-care. Further, routine passive self-care behaviors contrast to the standard advice given by health care professionals about how to respond to symptoms [20].

Bothersomeness was worse than severity for most symptoms. This means that although patients were not newly diagnosed and may have already lived with a disease for a long time, they may still be bothered by their symptoms and this bothersomeness can be variable over time. In

other words, one day a patient may experience severe symptoms but not be bothered, while on another day the patient may feel more bothered by the same severity. The bothersomeness (interference) of pain, as opposed to pain severity, has been shown to be more important in explaining disability in the context of chronic pain; [35] but, our findings about symptom bothersomeness across symptoms are unique. Variability and complexity of symptom characteristics call for an assessment of each person's multidimensional symptom profile to contribute to better education about symptom management.

4.2. Strengths and limitations

The primary strength of this work is the intensive, repeated measurement of symptoms. Although symptoms are acknowledged as important contributors to quality of life, they are typically studied as manifestations of specific diseases. When a symptom cannot be linked to a specific physiological cause, clinicians tend to ignore it. In this study we used daily self-reports of symptom characteristics and thus were able to link those characteristics directly with self-reports of self-care behaviors, regardless of etiology.

A major limitation of this study was under-enrollment of people reporting certain symptoms. The sample size limited our ability to add additional covariates to the model. But in most cases, the small sample was offset in part by the large number of responses received over the two weeks of data collection. Additionally, we collected data for two weeks and a longer duration may be necessary to capture sufficient adaptations in self-care management behaviors. A limitation to the data collection method was that we cannot be certain whether the same participant would rate the same symptom experience in the same way on different days. Cultural beliefs about health and diverse health care systems may have influenced responses but we compensated for this with our prior work [20] and local research staff. The study's convenience sample was also not diverse in education, financial security, or gender. Most participants enrolled in Europe; only a small number of people in the USA enrolled in the study. Yet, the completion rate overall was adequate, and participants responded to most EDA prompts.

4.3. Recommendations for further research

Additional studies of symptom characteristics, regardless of disease, are needed to guide our patient education approaches. A larger replication study is needed. We used single-item ratings, not validated questionnaires, to measure symptoms, but evaluation of the convergent validity of the EDA ratings in relation to validated questionnaires is a direction for further research. Further research is needed to explore causal attributions, especially since so few participants credited their symptoms to a change in their chronic illness. The Illness Perception Questionnaire may be useful for further exploration of symptom causal attributions [36]. Research is also needed to understand why fatigue and pain, symptoms that are largely treatable, were often met with a passive response. We found EDA particularly useful as a method of identifying what symptoms were experienced and the behaviors performed in response and recommend this approach for future research.

4.4. Conclusion

A focus on symptom characteristics, regardless of the clinical diagnosis, may promote a more thorough understanding of the patient's experience. Understanding how symptom characteristics influence illness behaviors can guide the development of interventions that help clinicians in providing more effective patient education and counseling.

4.5. Practice implications

The implication of these results is that it is vital to engage patients in an active assessment of their symptoms, including their self-care

behaviors. We recommend a stepwise approach where patients learn to (a) explore the nature of their symptoms and their response to symptoms; (b) recognize common symptom triggers and cognitive/affective barriers to symptom management; (c) identify appropriate and feasible symptom management options, and (d) choose primary and secondary symptom management options that can be used when symptoms occur. Patients seemed to have a default response to their symptoms, regardless of previous effectiveness. That is, they generally do not try alternative options that might be more effective, but patients can be taught to build skills in experimenting with different options in response to a symptom experienced. Adopting such an approach in clinical practice might challenge patients to try different options until they find what works best for them and their symptoms.

CRediT authorship contribution statement

Douglas Wiebe: Writing – review & editing, Methodology. **Tiny Jaarsma:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Ercole Vellone:** Writing – review & editing, Writing – original draft, Methodology, Investigation. **Heleen Westland:** Writing – review & editing, Writing – original draft, Methodology, Investigation. **Michelle M. van Rijn:** Writing – review & editing, Methodology, Investigation. **Sara Pettersson:** Writing – review & editing, Methodology, Investigation. **Christopher S Lee:** Writing – review & editing, Writing – original draft, Methodology. **Andrew Belfiglio:** Writing – original draft, Visualization, Methodology, Investigation, Data curation. **Kenneth Freedland:** Writing – review & editing, Writing – original draft, Methodology, Investigation. **Anna Stromberg:** Writing – review & editing, Writing – original draft, Methodology. **Barbara Riegel:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Conceptualization. **Shayleigh Page:** Writing – review & editing, Writing – original draft, Methodology, Investigation. **Subhash Aryal:** Writing – original draft, Methodology, Formal analysis, Data curation.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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