

Patterns of self-care decision-making and associated factors: A cross-sectional observational study

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ABSTRACT

Objective: The aim of this study was to identify for the first time patterns of self-care decision-making (i.e. the extent to which participants viewed contextual factors influencing decisions about symptoms) and associated factors among community-dwelling adults with chronic illness.

Methods: This was a secondary analysis of data collected during the development and psychometric evaluation of the 27-item Self-Care Decisions Inventory that is based on Naturalistic Decision-Making ($n = 430$, average age = 54.9 ± 16.2 years, 70.2 % female, 87.0 % Caucasian, average number of chronic conditions = 3.6 ± 2.8). Latent class mixture modeling was used to identify patterns among contextual factors that influence self-care decision-making under the domains of external, urgency, uncertainty, cognitive/affective, waiting/cue competition, and concealment. Multivariate multinomial regression was used to identify additional socio-demographic, clinical, and self-care behavior factors that were different across the patterns of self-care decision-making.

Results: Three patterns of self-care decision-making were identified in a cohort of 430 adults. A 'maintainers' pattern (48.1 %) consisted of adults with limited contextual influences on self-care decision-making except for urgency. A 'highly uncertain' pattern (23.0 %) consisted of adults whose self-care decision-making was largely driven by uncertainty about the cause or meaning of the symptom. A 'distressed concealers' pattern (28.8 %) consisted of adults whose self-care decision-making was highly influenced by external factors, cognitive/affective factors and concealment. Age, education, financial security and specific symptoms were significantly different across the three patterns in multivariate models.

Conclusion: Adults living with chronic illness vary in the extent to which contextual factors influence decisions they make about symptoms, and would therefore benefit from different interventions.

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What is already known

- How patients monitor for and respond to symptoms when they occur is assumed to be an essential component of self-care of chronic illness.

- We know very little about self-care decision-making in response to symptoms; Naturalistic Decision-Making and the new related measure are helpful in understanding this phenomenon.

What this paper adds

- Adults living with chronic illness vary as to the ways in which contextual factors influence the decisions they make in response to symptoms.

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- There are three common patterns of self-care decision-making among patients with chronic illness: *maintainers*, *highly uncertain individuals*, and *distressed concealers*.
- Age, education, financial security, and specific symptoms may help differentiate among self-care decision-making patterns.

1. Introduction

The prevalence of chronic illness and subsequent rates of related death and disability are on the rise globally (Diseases and Injuries, 2020). Adults living with chronic illness experience physical and affective symptoms that diminish quality of life (Megari, 2013) and contribute to disability (Hung et al., 2012) as well as make it challenging for patients to integrate chronic illness into their lives (Whittemore and Dixon, 2008). From the Middle Range Theory of Self-Care of Chronic Illness, we know that how patients adhere to prescribed therapies (i.e. self-care maintenance behaviors), how they monitor for symptoms (i.e. self-care monitoring behaviors), and how they respond to symptoms when they occur (i.e. self-care management behaviors) are essential components of self-care and disease management more broadly (Riegel et al., 2012). We also know from subsequent modification of the Theory of Self-Care of Chronic Illness that symptoms interact most directly with self-care monitoring and management behaviors (Riegel et al., 2019). An enduring gap in our knowledge about self-care of chronic illness, however, is the lack of insight into which factors influence self-care decisions about symptoms (i.e. self-care decision-making). That is, we have limited insight into which contextual or situational factors such as urgency (Watt, 2000) or uncertainty (Mishel, 1981) influence self-care decisions in response to the occurrence of symptoms, and are thus missing information on key links between self-care monitoring and management behaviors.

1.1. Models related to self-care decision-making

There are several models that are of potential benefit to our understanding about which factors influence self-care decision-making. First, health-related locus of control and related models center on the extent to which people believe that their health and related outcomes are determined by their own actions, determined by chance, or determined by others (Wallston et al., 1978). Generally viewed as a stable trait over time, health-related locus of control has been measured in direct association with perceived health (i.e. better health with internal health locus of control vs. chance or external loci) (Berglund et al., 2014), and as a moderator between empowerment and self-care behaviors in chronic illness (Wang et al., 2022). Health-related locus of control could help explain how decisions are made in response to symptoms; but, this model is not focused on either contextual or situational factors, and locus of control is a stable trait and therefore not readily amendable to intervention.

Second, the Health Belief Model centers on individual beliefs about health conditions and the key factors that influence health behaviors (Maiman and Becker, 1974). Elements of the Health Belief Model that are most informative in understanding chronic illness are *perceived severity* (i.e. beliefs about leaving the illness untreated considering the personal and social consequences of inaction), *perceived benefits* (i.e. beliefs about the effectiveness of actions used to manage illness and their benefit), *perceived barriers* (i.e. beliefs about barriers to management including cost–benefit considerations like expense, difficulty or danger), and *cues to action* (i.e. the perceived internal or external nature of decision-making triggers). The Health Belief Model has been used to explain variation in self-care behaviors among adults with diabetes (Melkamu et al., 2021); but, the roots of this theory are based on illness prevention not chronic illness management (Rosenstock, 1974), and the model is dependent on patient always weighing the outcomes of decisions rationally.

Third, the Conflict Theory of Decision-Making centers on the notion that the need to make decisions is driven by stress-inducing conflicts

(Janis and Mann, 1979). According to the theory, it is the awareness of the seriousness of risk in a) the absence of action, b) hope of finding a better alternative, or c) belief that there is enough time to learn more and choose among multiple options that determine which coping pattern will be used (de Heredia et al., 2004). A benefit of using the Conflict Theory in the study of decision-making is the accompanying Melbourne Decision-making Questionnaire (Mann et al., 1998) that is based on the theory-derived coping patterns of *vigilance* (i.e. careful, thorough and rational), *hypervigilance* (i.e. hurried or anxious), *procrastination* (i.e. delaying), and *buck passing* (i.e. avoidance or leaving decisions to others). Application of the Conflict Theory of Decision-Making is best used when studying how people make decisions in general as opposed to understanding contextual and situational factors that influence self-care decisions about symptoms.

Fourth, Hamilton and colleagues developed the Rational and Intuitive Decision Styles Scale (Hamilton et al., 2016) that measures decision-making styles but also captures elements of Big Five personality traits and components of linearity of thinking and rationality. That is, in this model rational decision styles are associated significantly with conscientiousness, openness to experience and agreeableness, and intuitive decision styles are associated positively with nonlinear decision-making and associated negatively with rational ability and engagement. Similar to the Conflict Theory, the Rational and Intuitive Decisions Styles are helpful in studying how people make decisions in general, but not specifically how people with chronic illness make self-care decisions in response to symptoms when they occur.

Finally, Naturalistic Decision-Making is centered on how people make decisions using experience and in response to contextual and situational factors (Zsombok and Klein, 1997). According to Naturalistic Decision-Making, factors such as *urgency* (e.g. the symptom may be different than previously experienced, or this time with a sudden onset), *uncertainty* (e.g. the reasons for the symptom are ambiguous, or there is conflicting information about what to do), *time pressure* (e.g. the symptom may be getting worse over time), *high stakes* (e.g. high distress and/or concern about inaction) and *concealment* (e.g. concern about others finding out) can influence decisions as important contextual or situational factors. Naturalistic Decision-Making focuses on real-world decisions that are imperfect, chaotic and often based on poor or missing information as opposed to the rational decision-making embedded in other theories. Moreover, Naturalistic Decision-Making also serves as a major theoretical underpinning of the Middle Range Theory of Self-Care of Chronic Illness (Riegel et al., 2012). As such, Naturalistic Decision-Making serves as the theoretical underpinning of this study because of its real-world appeal, direct employment in broader Self-Care theory, and theoretical underpinning of a new measure of self-care decision-making.

1.2. A new measure of self-care decision-making

Two major recommendations in decision-making research include a) a more theory-driven selection of measures, and b) a reduced emphasis on direct effects and more emphasis on interaction among individual decision drivers with an emphasis on contextual and situational factors (Appelt et al., 2011). To help address this first recommendation, the Self-Care Decisions Inventory was developed recently as a measure of the extent to which contextual domains influence patients' decisions about symptoms of chronic illness (Page et al., 2022). Based on the principles of Naturalistic Decision-Making, the Self-Care Decisions Inventory includes 6 contextual domains that influence self-care decision-making in response to symptoms: *external*, *urgency*, *uncertainty*, *cognitive/affective*, *waiting/cue competition* and *concealment*. Identifying common patterns among contextual factors that influence self-care decision-making would allow us to address the second recommendation above by emphasizing interactions among factors and focusing on context and situational factors. Moreover, identification of common patterns of how these contextual domains influence decision-making would get us closer to being

able to developing tailored interventions that first integrate and then enhance self-care decision-making.

1.3. Purpose

The purpose of this study was to determine whether multiple patterns of self-care decision-making could be identified in the context of chronic illness. Moreover, we aimed to identify socio-demographic, clinical and self-care behaviors that also were different across patterns of self-care decision-making.

2. Methods

This study was a secondary analysis of data collected during the development and psychometric testing of the Self-Care Decisions Inventory (Page et al., 2022). In brief, participants were recruited from across the United States via Researchmatch.org, a U.S. National Institutes of Health-sponsored platform designed to link researchers with potential participants. Eligibility criteria included being 18 years of age or greater, having at least one chronic condition (i.e. hypertension, coronary artery disease, cardiac arrhythmias, hyperlipidemia, stroke, arthritis, asthma, autism spectrum disorder, cancer, chronic kidney disease, chronic obstructive pulmonary disease, dementia, depression, diabetes mellitus, hepatitis, human immunodeficiency virus, osteoporosis, schizophrenia, and/or substance abuse disorders) (Goodman et al., 2013) and having at least one symptom of the chronic illness. Invitations were sent to a random sample of 1500 participants (of more than >50,000 potential participants at that time) meeting these criteria as entered into ResearchMatch. Eligible and willing participants agreed to have their contact information shared with the team via the secured platform. Potential participants (n = 1127) were then sent a unique link to provide consent and complete survey information (431 were willing and able to do so) using Qualtrics (Provo, UT) – the study was not otherwise open to the public or advertised online. The main product of the primary study was the new Self-Care Decisions Inventory described below.

2.1. Measures

Based on Naturalistic Decision-Making, the Self-Care Decisions Inventory consists of 27 items that inquire about the extent to which contextual factors influence self-care decisions in response to symptoms when they occur (Page et al., 2022). Table 1 presents the Self-Care

Decisions Inventory scales, scale-specific items, and scale interpretation. Each item is evaluated on a scale from 1 (no influence) to 5 (a lot of influence). A 6-factor multidimensional structure was identified with good multidimensional reliability (factor determinacy score = 0.86). The six contextual factors of the Self-Care Decisions Inventory are *external*, *urgency*, *uncertainty*, *cognitive/affective*, *waiting/cue competition*, and *concealment*. Each contextual factor is standardized to range from 0 to 100 to assist in interpretation with high values indicating that decisions about self-care were highly influenced by that factor.

Self-care of chronic illness was measured using the Self-Care of Chronic Illness Inventory (Riegel et al., 2018), a 20-item self-report measure that is based on the Theory of Self-Care of Chronic Illness and in turn rooted in Naturalistic Decision-Making (Riegel et al., 2012). The Self-Care of Chronic Illness Inventory includes three scales: self-care maintenance (i.e. *maintaining physiological stability and preventing unplanned healthcare utilization*), self-care monitoring (i.e. *active monitoring for changes of signs and symptoms*), and self-care management (i.e. *the responses to symptoms when they occur*) behaviors. Scores are standardized to range from 0 to 100 and higher scores indicate better self-care behaviors.

Sociodemographic and chronic illness data also were collected by self-report via the survey. Sociodemographic data included age, gender (male, female or other), race (White, Black, Native American/Alaskan Native, Asian, Native Hawaiian/Pacific Islander, or mixed race), ethnicity (Hispanic or Non-Hispanic), education (less than high school, some college, Associate's degree, Bachelor's degree, Master's degree, Professional degree (e.g. Medical Doctor or Juris Doctorate), Doctoral degree (PhD), or other), finances (have more than enough to make ends meet, have enough to make ends meet, do not have enough to make ends meet), and employment (full time, part time, unemployed, unable to work due to illness/disability, retired, or other). Comorbidities were assessed using the interview version of the Charlson Comorbidity Index (Charlson et al., 1987). Specific chronic conditions of participants, and the specific symptom they experienced and chose to reflect upon in answering the surveys were assessed in separate free text fields. Common chronic conditions (i.e. reported by ≥ 10% of the sample) were identified and aggregated using free text searches and counting in NVivo (Denver, CO), and then created into non-mutually exclusive dummy codes. Common specific symptoms (i.e. reported by ≥ 5% of the sample) *participants were thinking about in responding to the survey* were identified in the parent study using investigator free text searches, and further refined for the current study using the same approach above.

Table 1

The self-care decision inventory scales, items and interpretation.

Scale	Items	Interpretation
External	<i>Others gave me advice; others helped me to make a decision; different people gave different advice about my symptom; someone else recognized the symptom before I did</i>	The degree to which input from other people influences self-care decision-making.
Urgency	<i>I thought about decisions I made in the past when I had a similar symptom; the symptom got worse suddenly; when I had this symptom; I knew something was wrong; the symptom was severe or bothersome; I felt like something bad was going to happen; I felt I needed to make a decision quickly</i>	The degree to which the perception of urgency or high stakes influences the patient's self-care decision-making.
Uncertainty	<i>The symptom was different than what I expected; it wasn't clear to me what was causing the symptom; I didn't know what the symptom meant; I thought the symptom might be due to something else; I wasn't sure how important the symptom was; when I had the symptom; I didn't understand what was happening; the symptom was new to me; I recognized this symptom from the last time I had it; the symptom was different than the last time I had it</i>	The degree to which uncertainty or ambiguity, from incomplete information and/or difficulty interpreting the symptom, influences decision-making.
Cognitive/affective	<i>I felt too sad to make a decision; my thinking was not clear so I could not make a decision; I felt too anxious to make a decision; I didn't feel well enough to make a decision; I felt too tired to make a decision; I felt uncertain about what to do</i>	The degree to which the patient's thoughts or feelings influence decision-making.
Waiting/cue competition	<i>Other things were more important at the time; I thought I could wait to make a decision; I felt that the symptom was nothing to worry about; the symptom changed slowly; I thought I could tolerate the symptom; someone else needed my attention; I thought the symptom would go away on its own</i>	The degree to which situational factors delay decision-making.
Concealment	<i>I felt embarrassed about my symptom; I didn't want to burden my family; I didn't want people to know about my symptom</i>	The degree to which a desire to hide the symptom from others influences decision-making.

2.2. Statistical methods

Means and standard deviations (continuous variables) or count and proportions (categorical data) were used to describe the results where appropriate. Data on self-reported race were dichotomized to Caucasian vs. non-Caucasian because of limited sample diversity ($\approx 87\%$ Caucasian among 7 original categories). Educational categories were dichotomized into categories of <4 years of college or ≥ 4 years of college to consolidate small/empty cells. Data on finances were reduced from 3 to 2 categories – not enough to make ends meet vs. enough to make ends meet (enough and more than enough to make ends meet) to allow for meaningful comparisons. Data on employment were reduced from 6 to 4 categories of working, unemployed, disabled and retired to consolidate small/empty cells. Data on specific chronic conditions and symptoms are presented in categories developed from original free text responses as outlined above.

Latent class mixture modeling is a person-centered (vs. variable-centered) approach that results in the identification of statistically distinct patterns among multiple variables. We used latent class mixture modeling to identify two or more patterns of self-care decisions in response to symptoms using the categorical responses to the 27 Self-Care Decisions Inventory items (Table 1). Our approach to mixture modeling (Lee et al., 2020) is based on guidance from Ram and Grimm (2009), and accordingly judgment about the best number of patterns is based on several pieces of information: a) Bayesian Information Criteria (closest value to 1 indicates the best solution) (Nylund et al., 2007), b) classification probabilities (summaries of probabilities estimated within each class based on the most likely class to which all participants were assigned; values ≥ 0.95 indicate very limited uncertainty in classification), c) entropy (summary metric of certainty and uncertainty in how participants were assigned to classes; values > 0.8 commonly used as indicating limited uncertainty in how participants

were classified), d) the Lo–Mendell–Rubin Likelihood Ratio Test (Lo et al., 2001) (likelihood ratio test of difference in fit between models with a corrected distribution; p-values < 0.05 indicate a better solution), e) Parametric Bootstrap Likelihood Ratio Test (likelihood ratio test of difference in fit between models where empirical estimates are generated via bootstrapping; p-values < 0.05 indicate a better solution), and f) pattern size (no less than 5 % of the sample at large). The null hypothesis in latent class mixture modeling is that the sample is homogeneous regarding the model indicators (i.e. contextual factors influenced self-care decisions of all participants similarly in this analysis). To determine whether multiple patterns of self-care decision-making could be identified (*primary research hypothesis*), latent class mixture models ranging from 2 to 8 patterns were evaluated in an iterative approach and the best solution was based on the above criteria.

Unadjusted comparisons among patterns were made with analysis of variance or chi-squared tests where appropriate. The purpose of this step was to determine if the distinct patterns of self-care decision-making identified by latent class modeling were also different by factors not included in the model including socio-demographics, clinical characteristics and self-care behaviors (*secondary research hypothesis*). Multivariate multinomial (three category) regression was used to assess the relative risk of belonging in different self-care decision patterns based on factors that were shown to be statistically significant in unadjusted models (presented in Table 2). For the final multivariate multinomial regression, backward stepwise elimination ($p < 0.020$ by convention) was used for model selection – results are reported in relative risk ratios (RRRs), 95 % confidence intervals (CIs), and associated p-values. The purpose of the multivariate step was to identify a parsimonious list of factors that were associated with the patterns of self-care decision-making (*secondary research hypothesis*). All statistical analyses were performed in MPlus (v8; Los Angeles, CA) or Stata (v18; College Station, Texas).

Table 2
Characteristics of the sample overall and by pattern of self-care decision-making.

	Total (n = 430)	Maintainers (n = 207)	Highly uncertain (n = 99)	Distressed concealers (n = 124)	p-Value
Age (years)	54.9 \pm 16.2	58.3 \pm 15.0	56.2 \pm 16.0	48.3 \pm 16.3	<0.001
Gender (female)	302 (70.2 %)	148 (71.5 %)	71 (71.7 %)	83 (66.9 %)	0.487
Caucasian	374 (87.0 %)	180 (87.0 %)	87 (87.9 %)	107 (86.3 %)	0.940
Non-Hispanic	407 (94.7 %)	196 (94.7 %)	95 (96.0 %)	116 (93.6 %)	0.704
Education					
<4 year college	147 (34.3 %)	55 (26.7 %)	39 (39.4 %)	53 (42.7 %)	
≥ 4 year college	282 (65.7 %)	151 (73.3 %)	60 (60.6 %)	71 (57.3 %)	0.006
Finances					
Not enough	89 (21.2 %)	32 (15.8 %)	16 (16.8 %)	41 (33.9 %)	
Enough	330 (78.8 %)	171 (84.3 %)	79 (83.2 %)	80 (66.1 %)	<0.001
Employment					
Working	163 (39.6 %)	71 (36.4 %)	38 (39.6 %)	54 (44.6 %)	
Unemployed	19 (4.6 %)	8 (4.1 %)	0 (0.0 %)	11 (9.1 %)	
Disabled	96 (23.3 %)	38 (19.5 %)	24 (25.0 %)	34 (28.1 %)	<0.001
Retired	134 (32.5 %)	78 (40.0 %)	34 (35.4 %)	22 (18.2 %)	
Charlson Index	1.1 \pm 1.5	1.2 \pm 1.6	1.1 \pm 1.2	0.9 \pm 1.5	0.023 ^a
# of conditions	3.6 \pm 2.8	3.6 \pm 2.7	3.9 \pm 3.3	3.5 \pm 2.5	0.939 ^a
Specific conditions					
Depression	77 (17.9 %)	27 (13.0 %)	11 (11.1 %)	39 (31.5 %)	<0.001
Arthritis	76 (17.7 %)	40 (19.3 %)	20 (20.2 %)	16 (12.9 %)	0.251
Hypertension	64 (14.9 %)	36 (17.4 %)	15 (15.2 %)	13 (10.5 %)	0.231
Diabetes mellitus	59 (13.7 %)	35 (16.9 %)	11 (11.1 %)	13 (10.5 %)	0.179
Asthma	55 (12.8 %)	32 (15.5 %)	10 (10.1 %)	13 (10.5 %)	0.279
Fibromyalgia	48 (11.2 %)	19 (9.2 %)	15 (15.2 %)	14 (11.3 %)	0.299
Anxiety	45 (10.5 %)	15 (7.3 %)	9 (9.1 %)	21 (16.9 %)	0.018
Chronic pain	45 (10.5 %)	18 (8.7 %)	10 (10.1 %)	17 (13.7 %)	0.350
Specific symptoms					
Pain	166 (38.6 %)	76 (36.7 %)	49 (49.5 %)	41 (33.1 %)	0.032
Respiratory	55 (12.8 %)	35 (16.9 %)	11 (11.1 %)	9 (7.3 %)	0.033
Weakness/fatigue	42 (9.8 %)	19 (9.2 %)	7 (7.1 %)	16 (12.9 %)	0.320
Affective	36 (8.4 %)	9 (4.4 %)	1 (1.0 %)	26 (21.0 %)	<0.001
Gastrointestinal/genitourinary	33 (7.7 %)	14 (6.8 %)	8 (8.1 %)	11 (8.9 %)	0.773
Hypo/hyperglycemia	23 (5.4 %)	14 (6.7 %)	3 (3.0 %)	6 (5.9 %)	0.380

^a By Kruskal–Wallis.

2.3. Pattern nomenclature

Data that informed the labeling of the patterns of self-care decision-making included a) key contextual factors that influence self-care decisions within each pattern, b) key differentiating contextual factors that influence self-care decisions differently across the patterns, c) self-care behaviors that were different across the patterns, and d) other socio-demographic and clinical characteristics that were different across the patterns. Final labeling was reached by team consensus.

3. Results

The sample ($n = 430$) had an average age of 54.9 ± 16.2 [median = 58, range 18–89] years, was predominantly female (70.2%), Caucasian (87.0%) and non-Hispanic (94.7%), with an average of 3.6 ± 2.8 chronic conditions (Table 2). Depression, arthritis, hypertension, diabetes mellitus and asthma were the most common chronic conditions reported in the sample. Pain was the most frequently reported symptom.

Based on responses to the Self-Care Decisions Inventory, 3 patterns of self-care decision-making were identified (entropy = 0.912, class probabilities exceeded 0.958, Lo–Mendell–Rubin Adjusted Likelihood Ratio Test = 601.03 ($p = 0.0016$), Parametric Bootstrapped Likelihood Ratio Test $p < 0.0001$ all favoring 3 vs. 2 patterns). Increasing the number of patterns resulted in greater model uncertainty, nonsignificant likelihood ratio tests and/or excessively small patterns (<5% of the sample).

Urgency was the most common factor driving self-care decisions in all three patterns (Table 3). In the first pattern ($n = 207$ (48.1%)), self-care decision-making was primarily influenced by urgency but less so compared with the other patterns. Self-care decision-making was not influenced very much by other people, uncertainty, thoughts and feelings, situational factors or the desire to hide symptoms from others compared with the other patterns (Fig. 1; Table 3). Participants fitting this pattern also were older, had the highest level of educational attainment, were more financially secure by self-report, were more often retired, had the highest number of comorbid conditions, lowest rates of anxiety, the highest prevalence of respiratory symptoms (Table 2), and the best self-care maintenance compared with the other patterns (Table 3). Based on these characteristics, we labeled participants fitting this first pattern of self-care decision-making as “Maintainers.”

In the second pattern ($n = 99$; 23.0%), uncertainty influenced self-care decision-making more than it did with the other patterns (Fig. 1, Table 3). Self-care decision-making among participants belonging to this second pattern also was influenced heavily by urgency or high stakes and situational factors, especially in comparison with the first pattern. Participants fitting this pattern also reported the lowest rates of depression and had more pain compared with the other patterns (Table 2). Based on these characteristics, we labeled participants fitting the second pattern of self-care decision-making “Highly Uncertain” individuals.

In the third pattern ($n = 124$; 28.8%), self-care decision-making was influenced more by other people, thoughts and feelings, and the desire to hide symptoms from others compared with the other patterns, and

this was the pattern wherein urgency had the greatest influence on self-care decision-making (Fig. 1, Table 3). Participants fitting this pattern were the youngest, least educated, least financially secure by self-report, and most actively working. They had the lowest number of comorbid conditions, the highest rates of depression and anxiety, the most affective symptoms, and the worst self-care maintenance compared with the other patterns (Tables 2 and 4). Based on these characteristics, we labeled participants fitting the third pattern “Distressed Concealers.”

The multivariate model predicting self-care decision-making pattern is presented in Table 5. Each additional year of age was associated with lower risk of being in the distressed concealers pattern compared with the maintainers pattern. Having four years of college education or greater was associated with markedly lower risk of being in the highly uncertain or distressed concealers patterns compared with the maintainers pattern. Having enough finances to make ends meet was associated with a lower risk of belonging in the distressed concealers pattern compared with the maintainers pattern. Having distressed symptoms was associated with a higher risk of belonging in the distressed concealers pattern compared with the maintainers pattern. Finally, having the symptom of pain was associated with a higher risk of belonging in the highly uncertain pattern compared with the maintainers pattern.

4. Discussion

In this sample of 430 adults with chronic illness, we identified three patterns of self-care decision-making (i.e. the extent to which contextual factors influence decisions about symptoms) that were rooted in Naturalistic Decision-Making. Urgency influenced self-care decision-making the most across all patterns. The ‘maintainers’ pattern consisted of adults with limited influences on self-care decision-making except for urgency. The ‘highly uncertain’ pattern consisted of adults whose self-care decision-making was driven primarily by urgency and uncertainty. The ‘distressed concealers’ pattern consisted of adults whose self-care decision-making was highly influenced by external factors, cognitive/affective factors and concealment in addition to urgency. Although only contextual factors that influence self-care decision-making were considered in pattern identification, several other factors including self-care maintenance behaviors, age, education, financial security and specific symptoms differed significantly across the three patterns. To the best of our knowledge, this is the first evidence of patterns of self-care decision-making and associated factors in the context of chronic illness. Moreover, we view the patterns of self-care decisions we identified as being complementary to the previously-identified patterns related to Conflict Theory (Mann et al., 1998) in that they cover broad contextual influences ranging from external factors to concealment as opposed to patterns of coping with stress related to having to make decisions, and related to Rational and Intuitive Decisions Styles (Hamilton et al., 2016) in that they are not linked to any specific personality trait, linearity of thinking, or rationality.

An important distinction in the study of individual differences in decision-making is that between state and trait characteristics. For many reasons, including the limited measurement model and cross-sectional design, we think of the observed patterns of self-care

Table 3
Self-care decision-making characteristics by pattern.

	Maintainers $n = 207$ (42.8%)	Highly uncertain $n = 99$ (23.0%)	Distressed concealers $n = 124$ (28.8%)	F, p-value
External	15.7 ± 16.5	31.2 ± 25.1	40.1 ± 26.1	51.8, <0.0001
Urgency	49.1 ± 24.4	64.8 ± 19.8	69.3 ± 17.4	39.1, <0.0001
Uncertainty	14.2 ± 12.1	59.1 ± 15.0	43.7 ± 22.4	289.6, <0.0001
Cognitive/affective	11.0 ± 14.1	15.5 ± 13.6	59.8 ± 17.3	440.2, <0.0001
Waiting/cue competition	30.0 ± 20.7	48.5 ± 21.7	50.0 ± 21.1	44.9, <0.0001
Concealment	21.3 ± 23.7	31.7 ± 24.4	60.2 ± 25.5	99.3, <0.0001

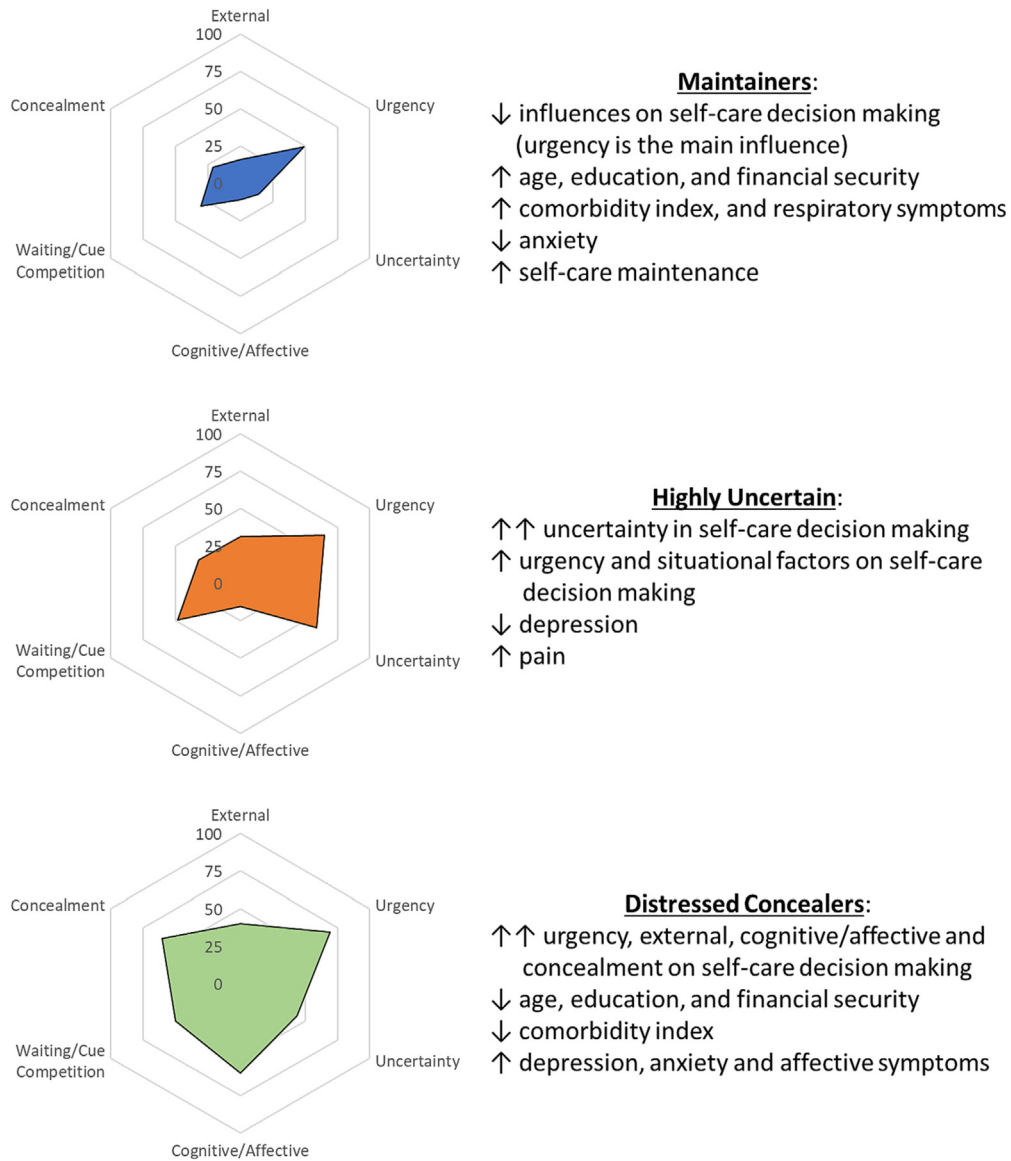


Fig. 1. Three patterns of self-care decision-making.

decision-making as state as opposed to trait characteristics. First, the items that helped identify these patterns were focused on contextual factors many of which change over the course of illness and even with seasonal variation. Second, and at least theoretically, the extent to which contextual factors influence decision-making is based in part on prior experiences. As such, there is learning that can occur and influence future self-care decisions.

We also like to think of the patterns of self-care decisions as being amenable to tailored intervention. For example, an intervention that is strength-based, and focused on preparing for changes in the trajectory of illness that are ahead may benefit *maintainers* the most. An

intervention that reduces uncertainty by improving interoceptive awareness or by using motivational interviewing to help patients learn what to do in response to symptoms may help *highly uncertain* individuals the most. Finally, like cognitive behavior therapy interventions that can mitigate affective symptoms, in combination with guideline directed medical therapy for affective disorders and specific training at the individual, dyadic or family level on effective communication to avoid concealment, may benefit *distressed concealers* the most. Minimally, interventions could be developed to minimize uncertainty and affective burden and help adults living with chronic illness to move toward a pattern of maintenance.

Table 4
Self-care behaviors by pattern of self-care decision-making.

	Maintainers n = 207 (42.8 %)	Highly uncertain n = 99 (23.0 %)	Distressed concealers n = 124 (28.8 %)	F, p-value
Self-care maintenance	76.0 ± 13.8	72.9 ± 15.8	69.6 ± 14.6	6.32, 0.002
Self-care monitoring	75.8 ± 18.6	78.4 ± 17.0	74.9 ± 17.9	0.87, 0.422
Self-care management	59.7 ± 18.1	64.2 ± 15.7	62.8 ± 17.1	2.63, 0.074

Table 5
Multivariate factors associated with self-care decision-making patterns.

	Highly uncertain		Distressed concealers	
	RRR (95 % CI) ^a	p-Value	RRR (95 % CI) ^a	p-Value
Age (in years)	–	–	0.963 (0.945–0.980)	<0.001
≥4 year college	0.487 (0.264–0.900)	0.022	0.552 (0.307–0.994)	0.048
Enough finances	–	–	0.429 (0.226–0.815)	0.010
Affective symptoms	–	–	3.929 (1.542–10.012)	0.004
Pain	1.944 (1.050–3.598)	0.034	–	–

CI = confidence interval, RRR = relative risk ratio.

^a The “Maintainers” pattern of self-care decision-making is the referent.

Our finding that urgency was the most common contextual factor driving self-care decisions is consistent with the Naturalistic Decision-Making underpinning of self-care of chronic illness in that real-world decisions about symptoms are dynamic and evolving (Zsombok and Klein, 1997) and must consider the degree of urgency and importance of symptoms. In the broad context of decision-making outside of chronic illness, it has been shown by others that adults make decisions to act based on perceived urgency over tasks with more significant outcomes (i.e. the so-called “mere urgency effect”) (Zhu et al., 2018). The urgency domain items on the Self-Care Decisions Inventory focus on both the urgency and perceived high stakes of the situation. Future research should help disambiguate perceived urgency from high stakes in order to help patients focus on whichever element of self-care decision-making results in the best short and long-term outcomes. Although we were able to provide evidence of contextual factors that influenced self-care decision-making in response to symptoms, we did not measure what actions were actually taken by participants. Moreover, the patterns we identified only differed in one aspect of self-care and not the behaviors typically associated with symptoms (Riegel et al., 2019). As such, future research will need to focus on specific symptoms that lead to specific decisions that lead to specific actions in order to gain a more comprehensive understanding of the link between self-care decision-making and both self-care monitoring and self-care management behaviors.

Age is an existing factor in both contemporary models of decision-making (Lockenhoff, 2018) and physical symptoms like dyspnea (Petersen et al., 2014). With the results of this study, we provide new insights into the potential role of age as a factor influencing self-care decision-making. It could be that by deferral or delegation, making decisions more quickly, drawing more on past experience, and adaptive affective evaluation, older patients resort to an only-when-needed, urgency-based self-care decision-making process as opposed to one that is blunted by cognitive/affective contextual influences or the need to conceal symptoms from family and/or friends. We also identified two main indicators or socioeconomic position in the World Health Organization model of the Social Determinants of Health (Solar and Irwin, 2010) as being important in the study of self-care decision-making. It could be that patients with chronic illness and less education and financial security have too many competing demands to make good decisions in response to symptoms and instead have that process inhibited by thoughts and feelings, and feel like the way to protect those around them is to conceal symptoms from them when they occur. It also could be that these individuals feel compelled to conceal their symptoms out of concern for the loss of employment or other types of stigma (Brouwers, 2020). But, gender and race, two other well established indicators of socioeconomic position, were not different across the three patterns of self-care decision-making. As such, our finding related to social determinant so health will need to be validated in a sample with more gender balance and racial diversity.

Finally, specific symptoms but not specific chronic illnesses, were helpful in differentiating among the three patterns of self-care decision-making. Hence, it may not be specific underlying conditions but instead the physical and affective manifestations of illness that help determine which pattern of self-care decision-making will be

used. In order to validate these findings, however, future research should focus on dismantling underlying conditions from symptoms in studies with tighter inclusion criteria and confirmation of chronic condition diagnoses as well as wherein symptoms are measured using valid and reliable methods as opposed to self-report and free text.

Several limitations to these findings should be considered when interpreting the results. First, this was a secondary analysis of data that were collected for the purpose of initial psychometric evaluation but not the identification of specific patterns of self-care decision-making. Second, the parent study was cross-sectional in nature and therefore limits our conclusions to the level of statistical association and not higher levels of inference. Third, the sample was relatively young compared with other samples of adults with chronic illness, and was relatively homogenous in terms of gender (70 % female), level of education (66 % ≥ 4 year college) and race (87 % Caucasian); as such, replication in a more diverse and representative sample is needed to overcome these threats to external validity. Finally, although our inclusion criteria included common chronic conditions, the specific chronic illnesses reported by participants and the symptoms they had in mind during survey completion were assessed by self-report and using free-text. Future research by this group and others should use more objective methods of evaluating the complexity and severity of multiple chronic illnesses and use more robust means of measuring symptoms as well as their severity and interference.

5. Conclusion

Adults living with chronic illness vary as to the ways in which contextual factors influence the decisions they make in response to symptoms. Sociodemographic factors and specific symptoms are helpful in differentiating among three common patterns of self-care decision-making. These patterns may be helpful in developing tailored interventions that can foster more effective self-care decisions in the context of chronic illness.

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Christopher S. Lee: Writing – review & editing, Writing – original draft, Visualization, Software, Methodology, Conceptualization. **Kenneth E. Freedland:** Writing – review & editing, Methodology, Conceptualization. **Tiny Jaarsma:** Writing – review & editing, Methodology, Conceptualization. **Anna Strömberg:** Writing – review & editing, Methodology. **Ercole Vellone:** Writing – review & editing, Methodology, Conceptualization. **Shayleigh Dickson Page:** Writing – review & editing, Project administration, Methodology, Data curation, Conceptualization. **Heleen Westland:** Writing – review & editing, Methodology. **Sara Pettersson:** Writing – review & editing, Methodology. **Michelle van Rijn:** Writing – review & editing, Methodology. **Subhash Aryal:** Writing – review & editing, Methodology. **Andrew Belfiglio:** Writing – review & editing, Methodology. **Douglas Wiebe:** Writing – review &

editing, Methodology. **Barbara Riegel**: Writing – review & editing, Methodology, Conceptualization.

Data availability

Summary data are available upon request to the corresponding author.

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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