

Integrating Symptoms Into the Middle-Range Theory of Self-Care of Chronic Illness

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The Middle-Range Theory of Self-Care of Chronic Illness has been used widely since it was first published in 2012. With the goal of theoretical refinement in mind, we evaluated the theory to identify areas where the theory lacked clarity and could be improved. The concept of self-care monitoring was determined to be underdeveloped. We do not yet know how the process of symptom monitoring influences the symptom appraisal process. Also, the manner in which self-care monitoring and self-care management are associated was thought to need refinement. As both of these issues relate to symptoms, we decided to enrich the Middle-Range Theory with knowledge from theories about symptoms. Here, we propose a revision to the Middle-Range Theory of Self-Care of Chronic Illness where symptoms are clearly integrated with the self-care behaviors of self-care maintenance, monitoring, and management.

Key words: *nursing theory, self-care, symptoms*

NURSING theory and nursing research are engaged in a dance that moves each forward with the goal of advancing nursing sci-

ence. Nursing theory is defined as “a creative and rigorous structuring of ideas that project a tentative, purposeful, and systematic view of phenomena.”^{1(p155)} Nursing research refers to research that provides evidence used to support nursing practice. Nursing theory needs to be based on and driven by research, and, in turn, nursing research needs to be derived from and contribute to theory if we are to successfully explain and predict patient experiences surrounding health and illness.

The theory-data cycle of development specifies that the empirical data derived from research serve to develop, revise, and refine theory whereas theory helps shape research questions, establish hypotheses, develop interventions, and select outcome variables (Figure 1). Theoretical propositions posed to describe or explain a complex reality can be tested in research, and the results of these studies can be used to further alter, expand, modify, or refine theory. Even in established and well-tested nursing theories, propositions remain tentative. When new research accumulates, theories may be revised or refined with the goal of creating solid evidence-based

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The authors gratefully acknowledge Karen Huss, PhD, RN, FAAN, for her review of a prior version of this article.

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The authors have disclosed that they have no significant relationships with, or financial interest in, any commercial companies pertaining to this article.

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DOI: 10.1097/ANS.000000000000237

Statement of Significance

- We know that self-care involves a process of health maintenance, monitoring for changes in signs and symptoms, and management of those changes when they occur.
- We know that symptoms influence self-care behaviors.
- This article describes *how* symptoms influence self-care behaviors. Specifically, this article describes the importance of symptom detection, interpretation, and response as core elements of the self-care process.

knowledge useful for guiding clinical practice. In this approach to theory development, there is a need for exploration, refinement, and critical reflection on the place and value of existing concepts and the need for expanding or developing others.

With the goal of theoretical refinement in mind, the purpose of this article was to evaluate the Middle-Range Theory of Self-Care

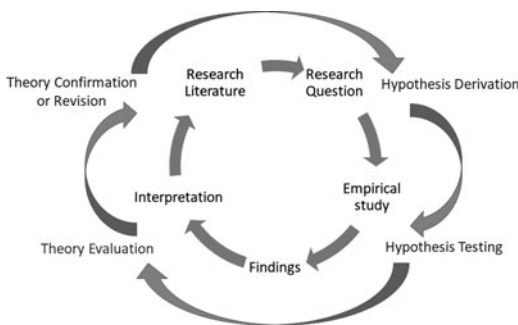


Figure 1. Graphic illustration of the manner in which the theory-data cycle of development builds science. Research questions are derived primarily from existing research literature. When these questions are tested empirically, the research findings are used to develop, revise, and refine theory. Theory helps shape subsequent research questions, establish hypotheses, develop interventions, and select outcome variables.

of Chronic Illness² to identify areas where empirical tests of the theory are likely to be problematic. We used Weber’s³ framework for theory development and evaluation to determine where the Middle-Range Theory of Self-Care of Chronic Illness² lacked clarity so that we could rectify issues by integrating concepts from other models and theories.

CURRENT STATE OF THE MIDDLE-RANGE THEORY OF SELF-CARE OF CHRONIC ILLNESS

The Middle-Range Theory of Self-Care of Chronic illness has gained the attention of clinicians and researchers worldwide, already resulting in 244 citations in the 6 years since publication. Work to date on the theory has successfully described the process of self-care behaviors in various populations and identified numerous factors affecting the self-care process.^{4,6}

As described in the original theory, self-care is performed in both healthy and ill states. It is important to note that everyone engages in some level of health-promoting self-care daily. However, self-care might have another meaning to patients with a chronic illness, since living optimally with a chronic illness often requires a set of behaviors to control the illness process, decrease the burden of symptoms, and improve survival.

Self-care is essential in the long-term management of chronic illnesses, and the purpose of the Middle-Range Theory of Self-Care of Chronic Illness² was to capture a holistic view of the manner in which patients with varied or multiple chronic conditions care for themselves. Self-care influences both clinical and person-centered outcomes in patients with chronic conditions. Those who engage more effectively in self-care have better quality of life,⁷⁻⁹ lower hospitalization rates,¹⁰⁻¹³ and less mortality than those who report poor self-care.¹⁴

In the Middle-Range Theory of Self-Care of Chronic Illness,² self-care is defined as a process of maintaining health—the central

phenomenon—through health-promoting practices and managing illness. These behaviors are performed in both healthy and ill states. Self-care can be seen as an overarching construct built from the 3 key concepts of self-care maintenance (eg, adherence to self-care behaviors such as regular exercise and taking medication as prescribed), self-care monitoring (eg, regular measurement of changes, routine testing), and self-care management (eg, changing the diet or medication dose based on detection and interpretation of symptoms). The 3 concepts of self-care maintenance, monitoring, and management are closely related; therefore, the performance of sufficient self-care encompasses all 3 behaviors.

For patients with chronic disease, it may be necessary to regulate and adapt self-care during the course of the disease, for example, with illness exacerbation, if a comorbid illness occurs, or if an advanced treatment is needed.² The goal of self-care maintenance is to maintain health and prevent symptom exacerbations, the goal of self-care monitoring is recognition that a change has occurred, and the goal of self-care management is effective treatment of symptoms.

Self-care behaviors reflect a sequence that builds on a foundation of self-care maintenance. That is, most patients first master self-care maintenance and later build expertise in self-care monitoring and management. People who perform all 3 behaviors are most proficient in self-care. However, for a variety of reasons, people with chronic illness often skip elements of the process, leading to problems in the successful performance of self-care.

After a thorough analysis of existing parts of the theory (eg, concepts, associations), we identified 2 important issues needing further development. First, the concept of self-care monitoring was determined to be underdeveloped. Relatively, little research has been conducted on the process of self-care monitoring, so more research may reveal what patients think about monitoring (eg, their response to engagement in body listening and routine appraisal for bodily changes) if monitoring of

signs (eg, blood pressure) differs from that of symptoms (eg, fatigue). We do not yet know how the process of monitoring interacts with the appraisal process. Are patients who monitor routinely more adept at judging changes? We anticipate that more research will lead to further revisions of the theory in the area of self-care monitoring. Second, the manner in which self-care monitoring and self-care management are associated is underdeveloped in the existing theory. Logically, those who do not monitor well probably do not management well, but this hypothesis has not been tested. As the Middle-Range Theory of Self-Care of Chronic Illness aims to describe and explain the process of maintaining health within the context of the symptom management required of those with a chronic illness and their families,² we decided to enrich the theory with knowledge from other theories about symptoms.

DESCRIPTION OF SYMPTOM THEORIES

There are numerous classic symptom theories used to guide research in nursing and related disciplines. We considered the Dynamic Symptom Model,^{15,16} the Theory of Unpleasant Symptoms,¹⁷ the Model of Pathways to Treatment,¹⁸ the Illness Action Model,¹⁹ the Symptoms Experience in Time Model,²⁰ the Situational Adaptation Model,²¹ Self-Regulation Theory,²² the Symptom Interpretation Model,²³ the Cognitive Perceptual Model of Symptom Perception,²⁴ Cue Competition Theory,²⁵ Kolk's Symptom Perception Model,²⁶ and the Psychophysiological Comparison Theory,^{27,28} because they complement the central arguments of the Middle-Range Theory of Self-Care of Chronic Illness in their description of symptoms or position self-care as an antecedent or consequence related to symptoms. Below we describe elements of the major symptom theories in nursing.^{17,29,30} In general, these theories aim to explain and predict symptoms as well as to describe how patients and caregivers appraise and act to control symptoms when they occur.

Self-care and symptom theories often address the same concepts. In the Dynamic Symptom Model,^{15,16} self-care is described as an antecedent of the symptom experience, symptom trajectory, and symptom consequences. However, self-care is not specially mentioned as an element of the intervention strategy to relieve symptoms. In the Middle-Range Theory of Self-Care of Chronic Illness, symptoms are described as important to monitor and as giving direction to self-care management behavior. That is, when symptoms increase, patients can use different management strategies, such as changing medication or diet or consulting a clinician. Detection, interpretation, and response are important elements of many symptom appraisal theories,³¹ and these concepts are vital parts of self-care monitoring and management in the Middle-Range Theory of Self-Care of Chronic Illness.

The symptom experience

Across existing symptom theories, symptoms are defined as subjective physical or mental experiences, appraised and defined by the patient, and reflective of an altered health state or change therein. For example, Lenz et al¹⁷ defined symptoms as subjective experiences and indicators of change in function as experience by the person. Dodd et al²⁹ defined symptoms as based on the perception of the individual experiencing the symptom and his or her self-report. Armstrong³⁰ stated that each symptom was individually defined by the patient. Insights from numerous lines of inquiry related to symptoms can be synthesized into the categories of *detecting*, *interpreting*, and *responding* to bodily changes (ie, symptoms). In the following section, we focus our attention on the detection and interpretation of bodily changes as symptoms. We address the response to symptoms as they occur during self-care, as described in the Middle-Range Theory of Self-Care of Chronic Illness.

Detecting bodily changes as symptoms

Several symptom theories are explicitly focused on symptom appraisal and start with

the detection of bodily changes.³¹ Bodily changes may be localized (eg, mid-sternal chest pain) or generalized (eg, fatigue) and can be detected by any of the body's senses. Theoretical discussions of symptoms specify that detection of bodily changes may reflect a difference in intensity and/or frequency of the patient's normal sensations that is sufficient in magnitude, novelty, or significance to be perceived.^{18,31} Detection of bodily changes causes a disturbance in equilibrium¹⁹ that drives patients to engage in self-care.³² As symptoms are detected, they must be interpreted with meaning applied to bodily changes, labeling them as symptoms. By definition, if a bodily change is not perceived, it is not a symptom.

Interpreting bodily changes as symptoms

The interpretation of bodily changes frequently involves characterizing the change and applying meaning. As an example of characterization, Lenz et al¹⁷ defined symptoms as entailing intensity (ie, severity, strength, and amount), quality (ie, what a symptom feels like, and location), duration (ie, frequency and duration of intermittent and persistent symptoms, and the temporal relationship between symptoms and activity), and distress (ie, the degree to which the person is bothered by the symptom(s)—reflective of how the patient interprets and experiences the meaning he or she assigns to it). Armstrong³⁰ defined the symptom experience as the perception of the frequency, intensity, distress, and meaning of symptoms as they are produced and expressed. Furthermore, Henly et al²⁰ defined the symptom experience as a flow process of evaluating and reevaluating symptom perception, timing, distress, intensity, and quality.

A salient theme across multiple symptom theories is that multiple symptoms frequently occur simultaneously and are multiplicative¹⁷ or catalytic in effect.³⁰ Moreover, certain symptoms (particularly those that are serious, unpleasant, or inexplicable)²⁰ draw

more energy in interpretation and eventual management.

With respect to the meaning applied to symptoms, bodily changes may be interpreted within social and cultural norms²¹; this can lead to stoicism or concealment of certain symptoms and overexpression of others as a function of what is perceived to be acceptable. Bodily changes may be interpreted as a function of emotion and illness representations²² including attribution (eg, fatigue from heart failure vs pulmonary disorder vs a normalized function of aging).²²⁻²⁴ Thus, the condition to which a symptom is attributed by the patient is inextricably linked to the meaning that is applied to the experience. Bodily changes may be interpreted differently depending on cognitive resources and external sensory input²⁴⁻²⁶; this includes external stress that may cause patients to be unaware of major body changes. Finally, bodily changes may be interpreted on the basis of motivation to maintain physiological stability.^{27,28}

Recently, Whitaker et al³¹ harmonized findings across many symptom theories to categorize antecedents preceding the detection and interpretation of bodily changes as knowledge (ie, familiarity, awareness, or understanding of bodily sensations acquired through experience or education), attention (ie, focusing on relevant stimuli while ignoring distractors), expectation (preexisting beliefs, contextual biases, and general heuristics or shortcuts), and identity (ie, distinct characteristics of an individual and his or her role in society). Specific to nursing symptom management theories, antecedents to interpreting bodily changes have been categorized as being physiological/disease-health related,^{17,20,29,30} personal,^{20,29,30} psychological,^{17,29} situational/ environmental,^{17,20} sociological,²⁹ and developmental factors.²⁹

Simply put, the process of detection, characterization, and meaning applied to bodily changes as symptoms is complicated. Hence, it is not surprising that the interpretation of bodily changes may be inaccurate (ie, mis-

interpretation of a bodily change or the absence thereof as a symptom)^{25,31} and highly variable among patients living with the same condition. Importantly, there is room for improvement in how the detection and interpretation of bodily changes as symptoms are incorporated into theories of self-care, which we address further in our discussion of future research.

Example integration of self-care and symptom theories

In the following, we provide an example to illustrate how to link the self-care perspective with the symptom management perspective. What would it look like if we studied heart failure from a *self-care perspective*? The patient with heart failure commonly experiences a variety of disabling symptoms that are exacerbated by missing medication doses, dietary indiscretions, and failure to maintain an active lifestyle. Using a self-care perspective, the patient and the clinician would focus on self-care with the goal of preventing symptoms. That is, symptoms are something to be avoided and self-care is a primary means of doing so. If symptoms occur, poor self-care might be suspected. The clinician might focus an assessment on reasons for poor self-care and interventions to improve various aspects of self-care, including monitoring of symptoms and responding to symptoms when they occur. Without more in-depth information on the symptoms experience, the patient and the clinician might overlook the complexity of symptom clusters^{33,34} and the different dimensions of the symptom experience. Advice might be focused on “what actions to take with this specific symptom” without seeing the total picture of how symptoms and the management of symptoms with self-care might interact. For example, increasing diuretics in response to dyspnea—a common self-care intervention—without considering the diurnal variation of the symptom experience could affect sleep patterns.

What would it look like if we studied heart failure from a *symptom perspective*?

Using symptom theory to guide care, attention would be given to the symptom itself (eg, severity and interference thereof) rather than addressing why it occurred. As noted in the National Institutes of Health (NIH) Symptom Science Model, complex symptoms, sequelae, and clusters of symptoms are studied through a disease agnostic lens.³⁵ The symptom phenotype is characterized using physiologic and biologic measures derived from genomics, proteomics, and metabolomics (ie, omics). Thorough understanding of the symptom experience may result, but the patient and the clinician also might overlook other important aspects of the situation that are not directly related to the symptom experience. For example, as described in a recent qualitative study, missing medication doses or dietary indiscretions may not be suspected if not temporally related to the symptom experience.³⁶

What would it look like if we studied heart failure from an *integrated approach*? An integrated approach might entail a more complete appreciation of the impact of symptoms on self-care and the influence of self-care on symptoms. For example, in the Situation-Specific Theory of Heart Failure Self-Care,³⁷ the concept of self-care monitoring from the Middle-Range Theory of Self-Care of Chronic Illness was operationalized in a unique and specific fashion for patients with heart failure because of their symptom issues. In the Middle-Range Theory, self-care monitoring is defined as the process of “observing oneself for changes in signs and symptoms.”^{2(p196)} But heart failure causes problems with the ability of patients to detect and interpret changes in signs and symptoms. Specifically, the insular cortex is the area of the brain responsible for interoception or the perception of sensations originating within the body.³⁸ However, lesions of the insular cortex have been found in patients with heart failure.³⁹ Even those patients with heart failure who are diligent in observing themselves for changes may not be successful in self-care monitoring because of these cognitive changes. Thus, we proposed a process that we named symptom

perception in the Situation-Specific Theory of Heart Failure Self-Care.³⁷ In that theory, symptom perception was said to involve body listening, monitoring, recognition, interpretation, and labeling of signs and symptoms. This is an example of how self-care and symptom theories can be integrated to achieve a more complete theory relevant to patients with heart failure. Importantly, an integrated approach would involve robust measurement of both symptoms and self-care, as advocated in the NIH Symptom Science Model.³⁵

PROPOSING A REVISION OF THE MIDDLE-RANGE THEORY INTEGRATING SYMPTOMS

At this point, recognizing the role of symptoms in patients' decisions regarding self-care behaviors, we propose that incorporating symptoms more explicitly into the Middle-Range Theory of Self-Care of Chronic Illness can help refine the theory and improve our ability to explain self-care and predict performance of self-care and the outcomes achieved. In the following, we use existing research to support proposed associations in the revised theory.

Self-care is fundamentally a decision-making process influenced by reflection.⁴⁰ Self-care theory is broader than symptom theory, but here we acknowledge the strong influence of symptoms on the self-care decision-making process. Symptoms themselves can be indicators of a bodily change, but research has confirmed that changes in the illness may not always cause symptoms.^{41,42} We also note that symptoms may or may not reflect an objective change in the chronic illness because detection and interpretation of bodily changes are complicated and imprecise processes.^{43,44} That is, some people may not be aware of changes in illness by objective measures because they do not detect or interpret those changes as symptoms. Conversely, symptoms may escalate in frequency and/or intensity in the absence of an objective change in illness. It is not unusual to see a

patient presenting to the clinician with a complaint of symptoms that cannot subsequently be attributed to a change in objective data. All of these factors influence the decisions that people make about self-care.

As shown in Figure 2 illustrating a proposed integration of symptoms into the Middle-Range Theory of Self-Care of Chronic Illness, symptoms influence various element of the self-care process. Specifically, people may be more willing to perform self-care maintenance and follow the treatment plan if they have symptoms. Research has shown that the experience of having symptoms can motivate chronically ill individuals to perform self-care.³² However, depressive symptoms and cognitive decline can blunt self-care by decreasing motivation to engage in healthy behaviors.⁴⁵⁻⁴⁷

We propose that symptoms interact most directly with self-care monitoring and self-care management. Active monitoring for symptoms is needed for awareness and interpretation of bodily changes as symptoms. At this point, we have integrated these processes into self-care monitoring. That is, even in someone who engages in tracking of his or her activity, signs, and symptoms, the self-care management response is not generated without awareness and interpretation of bodily changes as symptoms and the recognition of symptoms as being linked to

or attributed to a chronic condition. These processes have been shown to differ by clinical phenotype.^{48,49} For example, personality traits, gender, and age are known to influence symptom awareness, interpretation, and recognition.⁵⁰ Aging may blunt symptom perception.⁵¹ Somatic awareness has been found to be blunted in older persons with heart failure.^{52,53} Cultural and societal factors may influence the expression of symptoms.⁵⁴ There are also gender differences. For example, women may be more willing to acknowledge symptoms than men.⁵⁵

Logically, without symptom detection and interpretation, self-care management or the response to symptoms will not occur. Ideally, any self-care management behavior is followed by evaluation—a process of judging whether the behavior was helpful and should be repeated. The evaluation process is better in patients with better somatic awareness.⁵⁰

To summarize, symptoms are both an antecedent and a consequence of self-care. The experience of having symptoms can build skill in self-care maintenance, monitoring, and management.⁵⁶ As an antecedent, symptoms often motivate individuals to engage in self-care behaviors. Other antecedents include experience,⁵⁷ skill,⁵⁸ and self-care confidence or self-efficacy,⁵⁹ all of which can be influenced by the symptom experience, as described later. Cultural beliefs,⁶⁰ values,⁶¹

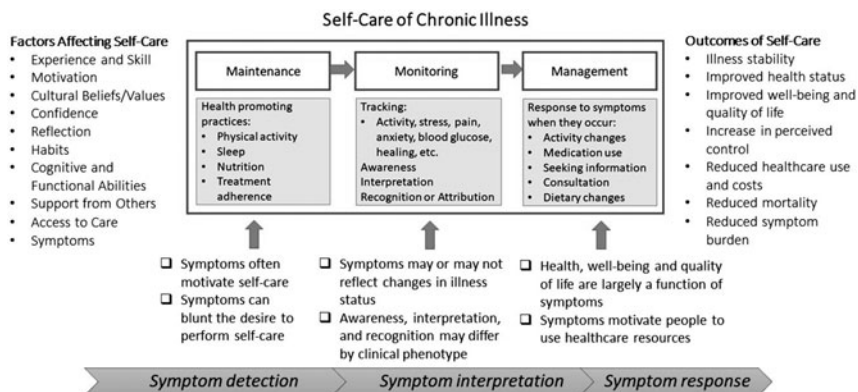


Figure 2. Model integrating symptoms with self-care as defined by the Middle-Range Theory of Self-Care of Chronic Illness. Although depicted here as linear, we see the self-care process as including feedback loops. Note that the overlap between the bottom arrows and core self-care model is both theoretical and imperfect and indeed a target of further refinement.

reflection,⁴⁰ habits,⁶² cognitive and functional abilities,⁶³ support from others,⁶³⁻⁶⁵ and access to health care⁶⁰ all influence the self-care process.

Consequences of self-care are shown in Figure 2 as outcomes. These outcomes include illness stability,⁶³ health,⁶⁶ well-being, quality of life,⁷ perceived control,⁶⁷ and clinical outcomes such as the need for hospitalization,⁶³ health care costs,⁶⁸ and symptom burden.⁶⁹ Mortality risk is lower in patients receiving longer duration self-care interventions.⁷⁰ Perceived health, well-being, and quality of life are largely a function of symptoms. Although many people with chronic illness tolerate symptoms, severe symptoms were associated with poor quality of life.⁷ In another sample, symptoms were the primary reason why patients sought acute care.⁷¹ Thus, the control of costs associated with chronic illness may be addressed with symptom management strategies.

CONCLUSION

Weber³ argues that the most important contributions to knowledge development are theories that are developed sufficiently to allow for explanation and prediction. Thus,

our goal was to refine the Middle-Range Theory of Self-Care of Chronic illness to address 2 identified issues: (1) further development of the concept of self-care monitoring, and (2) further development of the manner in which self-care monitoring and self-care management are associated. We approached these issues by integrating symptom theory into the Middle-Range Theory of Self-Care of Chronic Illness.² The 2 perspectives—self-care and symptoms—are clearly related. By explicitly integrating them, our hope is that the contribution of symptom theory to self-care theory will be further developed and the ability of self-care to mitigate symptoms will be appreciated. Both perspectives are central to a holistic approach to patient care.

We believe that this integrated theory will be of use to both clinicians and scientists. Clinicians working with people with chronic illness are encouraged to embrace an assessment and intervention approach that integrates the impact of symptoms on self-care. Scientists are encouraged to test hypotheses derived from this refined theory to further our understanding of how the detection, interpretation, and response to symptoms can and should be incorporated into interventions designed to improve self-care.

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