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Care of Adults With Cardiovascular Disease

Knowledge among patients with heart failure: A narrative synthesis of qualitative research



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ABSTRACT

Background: Patients' knowledge of heart failure (HF) is integral to improved outcomes. However, the HF literature has not adequately explored the nature of patients' knowledge of HF as part of their lived experience. **Objectives:** We aimed to characterize the nature of patients' knowledge of HF, in the context of living with the disease.

Methods: We conducted a narrative synthesis of qualitative studies that addressed patients' knowledge of HF. Studies were systematically searched and retrieved from MEDLINE, CINAHL, PsycINFO and PsycARTICLES databases. Findings were synthesized using an iterative coding process carried out by multiple analysts and reported following Enhancing Transparency in the Reporting of Qualitative Health Research (ENTREQ) criteria.

Results: Analysis of 73 eligible articles produced five themes: the content that comprises HF knowledge; development of HF knowledge over time; application of HF knowledge for decision making; communication of information between clinicians and patients; and patients' experience of knowledge.

Conclusion: The nature of patients' knowledge of HF is both explicit and implicit, dynamic, and personal. This multidimensional model of knowledge-in-context calls for equally multidimensional research and intervention design.

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Introduction

For adults with heart failure (HF), possessing HF-related knowledge is essential to self-care.^{1–3} Such knowledge “increases perceived control and facilitates the patient's adaptation to the chronic illness role and self-care behavior” (p. 366).¹ Studies, some dating back to 1999, report an association between HF-related knowledge and medication adherence,⁴ self-care behavior,^{5,6} and the likelihood of hospitalization.⁷ According to reviews, most behavioral interventions for HF self-care have targeted knowledge, using educational or informational components.^{8–12} ACCF/AHA Guidelines for the Management of Heart Failure list education as a Class I (Strong) recommendation,¹³ in part because it is known to improve knowledge as well as adherence, acute care utilization, and health outcomes.^{13–15} Because many patients' HF-related knowledge is deficient despite abundant educational initiatives, knowledge and

education remain frequent subjects of HF research and interventions.^{4,5,16} Other work has examined the antecedents of knowledge, such as HF education or health literacy, as well as how education and other knowledge-modifying interventions affect adherence, health outcomes, and care utilization.^{15,16}

Many attempts have been made to measure patients' knowledge of HF. There are at least 12 English-language instruments to assess HF knowledge.¹⁷ However, these measures assess primarily the degree to which patients possess explicit or declarative knowledge content and, to a lesser extent, the ability to apply such knowledge. For example, a test might assess patients' ability to report how the heart functions or how to read a nutrition label.¹⁸ These measures are based on a static definition of knowledge-as-content. This definition represents a clinical perspective of knowledge that we contend should be complemented by a more patient-centered perspective, one that understands knowledge in the context of the dynamic experience of living with HF. Such a patient-centered understanding of knowledge-in-context is needed to ensure interventions on patients' knowledge of HF are equally patient-centered. Patient-centered interventions, characterized by attending to

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patients' values and beliefs, are known to improve knowledge, self-care, quality of life, and other outcomes.¹⁹

The present study's objective was to characterize the nature of patients' knowledge of HF, in the context of living with the disease. To address this objective, we conducted a narrative synthesis of published empirical literature. The review was performed on studies reporting qualitative research findings, as these were most likely to provide the broad coverage, depth of description, and access to original data in the form of quotations needed to understand knowledge in a comprehensive manner.²⁰ Qualitative data collected from patients are also ideal for depicting phenomena from the patient's perspective because these data represent the patient's experiences, beliefs, and behaviors, often in the patient's own words.²¹

To our knowledge, this was the first review to synthesize the qualitative literature on HF knowledge. Other reviews have examined related HF topics such as education and health literacy, primarily reviewing quantitative studies. Other studies have reviewed qualitative research on the lived experience of HF, but did not focus on knowledge.^{22,23} Although a number of individual studies have discussed the nature of HF knowledge,^{2,24} a broader synthesis of the literature is likely to reveal a fuller, consolidated view of patients' knowledge of HF. Based on the above-referenced prior work and relevant cognitive sciences literature,^{25–30} we anticipated this review would reveal HF-related knowledge as a complex, dynamic construct: both explicit and didactic as well as implicit and tacit; something that can be acquired over time, forgotten, or lost; and both declarative and procedural.

Methods

The review was a narrative synthesis³¹ of qualitative data from empirical literature. Studies were identified using systematic screen and search following the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA).³² Narrative synthesis is a method of analyzing the contents of publications to answer questions such as "what is it?" or "how does it work?", rather than "did it work?" and was therefore appropriate to our goals.³³ To report findings, we followed recommendations for synthesizing qualitative literature from Enhancing Transparency in the Reporting of Qualitative Health Research (ENTREQ).³⁴ All criteria were met except study appraisal, which we deemed outside the scope of the study.

We performed searches of electronic databases CINAHL (Nursing), MEDLINE (Medicine), and PsycINFO and PsycARTICLES (Psychology), from inception to March 2017, and subsequently repeated the search through July 2018. Search terms included 'heart failure' OR 'HF' AND 'patient' AND 'knowledge' or 'comprehension' or 'understanding' to retrieve all available studies related to patient knowledge of HF, with no additional filters applied. The term knowledge is a popular MeSH term and a nearly exclusive term for the construct. Although the terms 'comprehension' and 'understanding' were sometimes used in articles, these articles were also retrievable using the term 'knowledge.' Using the relatively small number of search terms, we retrieved a broad set of nearly 5000 articles including ones with HF knowledge as their central construct, as well as many others reporting on knowledge but focused on the HF disease trajectory, treatment, self-management, and end-of-life. Thus, for this narrative synthesis, we did not further expand the search strategy. However, we performed a subsequent hand search of references to identify additional publications that were not retrieved from the keyword search. Abstracts and titles, and subsequently full-text articles, were screened for the following inclusion criteria: 1) studied participants with HF; 2) included content on patient knowledge; 3) used a qualitative or mixed method design; 4) were written in English; and 5) were published in a peer-reviewed venue. Two analysts (authors CD and MA) performed full-text review and discussed inclusion and exclusion of articles

remaining after review of the titles and abstracts. Papers were arranged by their primary objectives, then for each, the analysts determined whether patient knowledge of HF was an *a priori* target of the study objectives, emerged in the study findings, or was not addressed (and therefore excluded). The analysts met weekly to discuss the content and findings of each article to develop a preliminary framework. The framework included guiding questions such as: (1) How do people acquire knowledge (where, from whom, in what setting, when)? (2) What happens to knowledge over time? (3) How and when is knowledge used? (4) What effect does experience (learning, self-care, decision making, personal discoveries) have on knowledge? (5) How do the findings describe or depict knowledge (more, better, different, inaccurate)? (6) What do patients want to know? (7) What are patients' attitudes and perceptions about knowledge?

After jointly reading approximately 40 papers, they divided the remaining papers to review individually. Articles were excluded at this stage if they reported only on informal caregiver or clinician knowledge, did not describe HF knowledge as part of the findings, or did not report qualitative data. One was excluded because it focused on the impact of culture on knowledge, which was out of scope for this review. The analysts systematically extracted relevant findings from the results of each study into NVivo 11.0, a qualitative analysis software tool used to organize the findings. The analysts divided the papers between them and read results line by line, placing findings into the categories of the preliminary framework, while also allowing subcategories to emerge from the data. Weekly discussions about the emerging categories promoted consistency and quality. Within categories and across all data, the analysts identified "patterns in the data" (p. 80)³⁵ related to the nature of knowledge among patients with HF, resulting in five primary themes. A senior researcher (author RH) supervised the process and provided feedback on the themes.

Results

We selected for analysis a final set of 73 articles (reporting on 71 unique studies)^{6,24,36–106} from 4968 initial citations (see Fig. 1 for PRISMA diagram). The studies used qualitative ($n = 63$, 88.7.0%) or mixed methods ($n = 8$, 11.3%) approaches. When reported, qualitative studies used methodologies such as grounded theory,^{24,36,53,72,81,88,89,98,101} phenomenology,^{50,51,82,83} inductive analysis,^{44,63,68,77,93,98,101} and deductive analysis.⁷⁴ All included adult patients with HF and 16 (22%) included both patients and others involved in the patient's care such as informal caregivers, family, or nurses (however only findings related to patients with HF were used). Study location was reported in 65 studies as the United States ($n = 27$), Canada ($n = 4$), UK ($n = 11$), Sweden ($n = 9$), Western Europe ($n = 4$), Asia and Pacific Islands ($n = 6$), Africa ($n = 1$), South America ($n = 1$), Australia ($n = 1$) and New Zealand ($n = 1$). The study characteristics are summarized in online Appendix A.

Five major themes describing the nature of patients' knowledge of HF emerged from the analysis: content, development, application, communication, and experience (see Table 1). The theme of knowledge content addressed the presence and accuracy of explicit information about HF diagnosis, treatment, and management. The theme of knowledge development addressed how patients with HF established knowledge, including information sources contributing to knowledge formation and the transformation of knowledge over time. The theme of knowledge application addressed how patients used HF-related knowledge in practice, including developing skills based on their knowledge. The theme of knowledge communication addressed the transfer and sharing of HF-related information between patients and clinicians. Finally, the theme of patients' experience of knowledge addressed how patients related to knowledge in the course of living with the illness, including their attitudes towards knowledge.

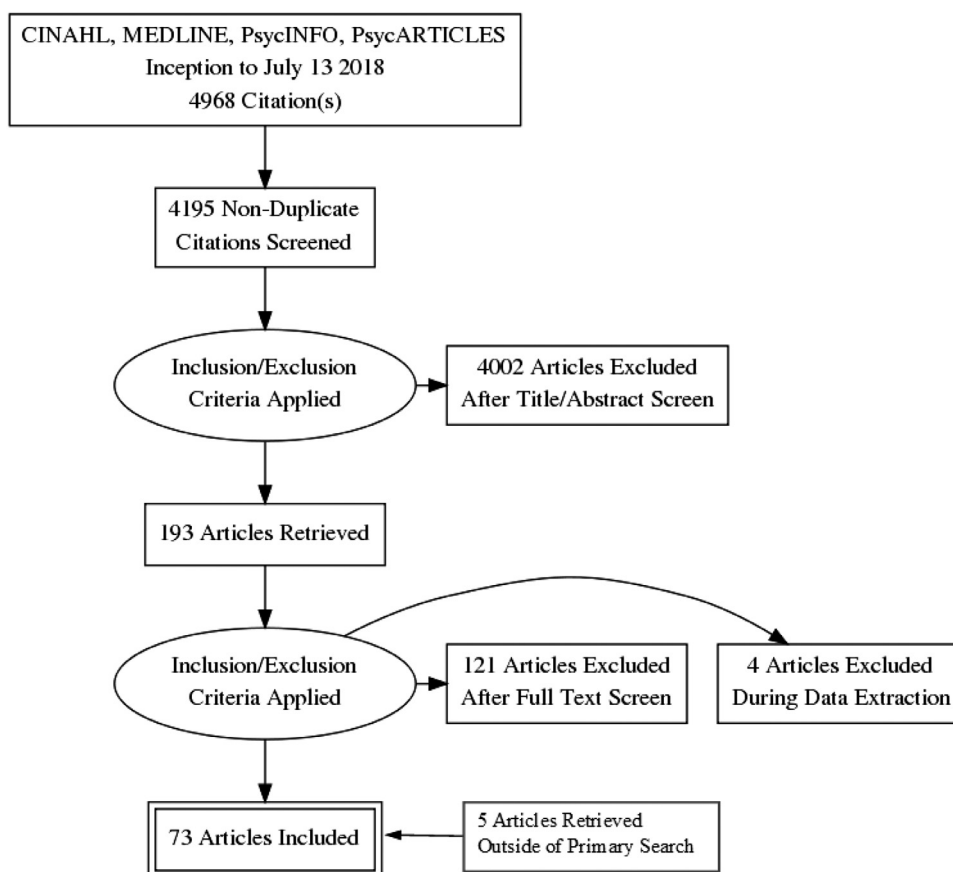


Fig. 1. PRISMA diagram of study selection.

Knowledge content: information that comprises knowledge

In several studies, patients attributed the etiology of HF to old age, stress, genetics, being overactive, other illnesses, and/or medications^{45,74,91,93} and believed fluid retention or shortness of breath caused HF.^{45,46} Patients attributed symptoms to other conditions such as a cold or flu virus, old age, stress, or behaviors such as drinking alcohol and smoking, lung problems, being out of shape, anxiety, medication side effects, or as something uncontrollable,^{40,45,48,64,69,70,75,81,85,87,89,91} for example: “I don’t know if it’s panic attacks I’m getting or if it’s to do with the medication or the condition...” (p. 1252).⁷⁴

In terms of ongoing maintenance of HF, Dickson et al. reported that patients understood instructions for self-management, illustrated by one patient: “If you gain 5 or more pounds you have to report it to your doctor because it means you’re retaining a lot of fluid” (p. 181).¹⁰³ However, studies also reported misconceptions about HF self-care that could lead to inappropriate action,^{48,62,86,102,103,106}

such as believing that all sodium can be abated by washing canned vegetables or eating fruit along with salty foods.¹⁰² Several studies suggested patients were aware of general self-care recommendations but had unanswered questions about specific instructions for performing the recommendation or reconciling it with other advice (Table 2).

Five studies described patients’ knowledge of the purpose and effects of medications.^{64,90,102,105,106} In one study, lack of medication knowledge led to difficulty differentiating between medication side effects and disease symptoms.⁹⁰ and another study reported that understanding medication effectiveness facilitated adherence.¹⁰⁵ In one study, not knowing how to self-administer medication was a patient-reported barrier to medication adherence.¹⁰⁴ Another study reported that knowing the purpose of a medication was not related to adherence, in the case of a patient who adhered to blood pressure medication despite believing it was prescribed for arrhythmia.¹⁰²

Table 1

Defining categories of knowledge of patients with heart failure (HF).

Theme	Description	Papers
Content	The presence and accuracy of explicit information about diagnosis, treatment, and management.	24,36–41,43–50,52–57,59,61,62,64,65,69–72,74–77,79–82,84–94,96–98,100–106
Development	The process by which patients establish knowledge, including information sources contributing to knowledge formation and transformation of knowledge over time.	6,40,42,43,49,55–57,60–62,64,66–68,72,73,78,83,85–88,90,94,95,98,100,102,105,106
Application	How patients use knowledge in practice, including developing skills based on their knowledge.	6,24,37,42,48,49,52,54,56,59,67,75,77,83,85–87,90,94,95,98,99,103,105,106
Communication Experience	The transfer and sharing of information between patients and clinicians. How patients relate to knowledge in the course of living with the illness.	36–39,41–45,49–51,53,61,63,70,71,73,79,85,87,88,91,92,96–98,100,105,106 24,36,38–45,49,53,57,61,63,66,72–75,77,78,83,86,87,89,91,93,94,96,100,101

Table 2
Self-care recommendations understood by patients but raising unanswered questions.

Self-care recommendation	Unanswered questions raised (examples)
Restrict sodium intake	<i>Which foods contain sodium?</i> ^{40,87,96,97}
Monitor weight gain	<i>How does diet (e.g., fat intake) and weight affect heart failure self-monitoring?</i> ^{61,62,77}
Restrict fluid intake	<i>Aren't fluids good to "flush out the system" and stay hydrated?</i> ⁶⁴
Engage in physical exercise	<i>How do I balance exercise with my need to rest?</i> ^{37,86,87,93}

Some patients' knowledge about the disease revealed inaccuracies, including the view of HF as an acute condition, curable or survivable and not terminal,^{24,36,43,53,57,92} and that HF medications can eventually be stopped.^{36,53,93} One study reported that patients' understanding of their condition as expressed in interviews did not align with the physician's notes, and that "participants' narratives of their understanding of their diagnosis integrated sporadic medical knowledge which was frequently misconstrued" (p. 6).⁸¹ In terms of outlook and prognosis, patients' beliefs were not always consistent with their clinicians'. In a study of palliative care consultation, although the entire sample of 24 patients with late-stage HF understood their prognosis, half disagreed with their clinician's prognosis and pursued a plan of care based on a more optimistic outlook.⁷⁶

Knowledge development: formation and transformation of knowledge over time

In the reviewed studies, patients obtained HF-related information from healthcare professionals,^{56,57,72,78,106} other family members and resources,⁹⁴ educational talks,⁶⁶ written materials,^{42,55–57,98,100} and the Internet.^{42,49} Some patients saw the benefit in sharing and receiving information with others who experience HF, as in support groups.^{94,100} One study described how patients learned by listening to nurses and built skills such as reading labels and changing eating patterns.⁸⁶ Another described patients teaching themselves about low-sodium diets, reading labels, and finding information independently.⁴⁰ Other studies showed that knowledge of HF symptoms came from personal, 'hands-on' experience.^{42,88}

Two studies revealed that patients' knowledge of HF evolved through a slow learning process of acquisition and integration.^{62,102} Methods to facilitate patients' learning included repetition (repeated instructions from more than one clinician, attending multiple educational sessions),⁴² sensemaking, problem solving, and trial and error.^{64,78}

Studies described how knowledge content and types of knowledge changed with experience.^{73,106} Patients described "phases," or adaptations to living with HF that involved adjustments to their lifestyle, realizing the HF was a lifelong condition.⁶⁸ In a study by Dickson and Riegel, patients described being "in tune" with their bodies and symptoms, making decisions based on prior successes or failures with managing symptoms.⁴⁹ Further, patients reported learning to "listen" to their bodies to recognize vague or unique symptoms, as well as creating adaptive self-monitoring strategies: "the ring... if it gets real tight, then I'll know I'm holding fluid" (p. 175),⁶ or, "I'm bloated today... I feel it in my stomach" (p. 240)¹⁰⁶ Other studies described patients who could link their symptoms to behaviors¹⁰⁶ and also linked behaviors (such as eating a high-salt diet) to the resulting symptoms (such as swelling in the legs) that eventually led to hospitalizations.⁹⁴ In one study a patient reflected, "I should have gone to the hospital sooner with shortness of breath... I didn't think it was anything serious" (p. 619).⁴⁵

Knowledge application: using knowledge to develop strategies and self-efficacy

Patients used their knowledge for strategies to manage HF in daily life, such as learning to recognize what deciliter units look like in a glass⁵² or assessing sodium content from nutrition labels and avoiding canned foods.⁸⁷ Other strategies involved tools or mnemonic devices: "I'm learning the importance of how the medicine works... so now I make sure... I even set the alarm so I take them on regular rhythms" (p. 278).⁹⁴

Two studies reported that patients who understand *what* to do may nevertheless lack information on *how* or *when* to do it, thus deterring or delaying appropriate action.^{37,49} Dickson and Riegel described applying HF-related knowledge as knowing how to do a task (tactical skill) as well as what to do and when to do it (situational skill).⁴⁹ Similarly, Albert et al. described patients who knew they needed to exercise, but did not know to what type of exercise to do or which exercises were safe for them.³⁷ In a study by Riegel et al., patients struggled to manage their diets in the context of comorbidities with different dietary requirements.¹⁰⁶ In a seminal study by Granger et al., physicians believed patients did not understand self-care recommendations, whereas patients reported knowledge of the recommendations but difficulty applying their knowledge in practice: "It's easy to understand. It is just not easy to do" (p. 311).⁵⁹

Knowledge communication: the contribution of patient-clinician communication to knowledge

Two studies revealed integrating information from a healthcare professional while a patient was forming or contemplating other questions was challenging, because patients were distracted and unable to pay full attention.^{42,91} Further, receiving instructions in the hospital was difficult for one patient due to "exhaustion, fear of dying, and powerlessness over even basic needs such as bathing and toileting during hospitalization" (p. 238–239).⁸⁷ Similarly, as explained in another study, "others said they had been given information at inappropriate times such as after a surgical procedure in hospital or when they were too shocked by the diagnosis to 'take it in'" (p. 626).⁵³

Some studies reported that patients felt inadequately informed by their cardiologists about their diagnosis.^{42,63,106} Rong et al. explained that patients attributed non-adherence and frequent clinic visits to not receiving sufficiently detailed information from their clinicians.⁹² In another study, a patient described how communication was limited: "There's a lack of dialogue and I'm not being asked. They say we should have a dialogue but they only give the test results" (p. 49).⁵¹ Further, patients believed physicians did not have enough time to explain during office visits or did not take the time to get to know the patient.^{38,45,71} Successful communication was also predicated on common language both the patient and healthcare professional understood, as key information could be lost in the translation between medical terminology and lay language.^{41,42,100}

Patient experience of knowledge: how patients relate to knowledge

Some patients with HF were reported to avoid obtaining and developing a more detailed level of knowledge due to fear, as illustrated in one study: "Well sometimes I feel as if I'd rather not know anything. I'd rather let things take its course, you know... I'd rather not know because it might scare me, you know. I just keep taking the drugs and it all just... I don't want to know." (p. 606).⁹¹ Two studies described how patients valued having awareness about their condition and treatments^{53,61} and two other studies revealed that patients were hesitant to ask questions and receive information because of anxiety.^{41,57} The fear of dying made learning information difficult: "(Y)ou can read about things but that is the hardest part – the fear of

just dying.” (p. 2035).⁴² One patient described how knowledge would not change their outcome and therefore was not worth the worry: “There’s nothing you can do about it, so why worry or think about when or how you are going to die?” (p. 222).³⁶ This reflected the belief that knowledge of prognosis could deprive them of hope and prevented living life in the moment.^{36,63}

On the other hand, studies revealed that knowledge and information helped reduce uncertainty and lower anxiety related to an unclear disease trajectory.^{43,61,73,89} Stull et al. revealed how not knowing the trajectory of the disease left patients feeling unsure about what to think and feel, or how to act, for example: “It’s hard to take, not knowing how long I was going to be sick. Still not knowing” (p. 288).¹⁰¹ Other patients desired to know the “whole truth and not only part of the truth” (p. 223),³⁶ including details about prognosis.^{38,63} Stull et al. also found that having HF led to uncertainty about one’s identity, possible social roles, and the future of oneself and life, thus reinforcing the importance of information about what HF is, what it means to be a patient with HF, and how to proceed in day-to-day life.¹⁰¹ A participant in a study by Lilje-roos et al. stated: “If I was to get worse, would you not think that it would be good to have more information about what’s happened and what to do next?” (p. 2932).⁷³

Agard et al. described how patients actively sought knowledge about HF, including its causes, definition, treatment, severity, and details about when to go to the hospital, daily instructions, and what to expect.³⁶ Other studies revealed that patients initially avoided knowledge but became more willing to learn about their condition over time,⁷² or began to pursue knowledge related to medications, an upcoming procedure, and clinicians’ treatment decisions.⁷⁸

One patient expressed a desire for more explanatory knowledge: “Why are my legs swelling up, why am I not getting rid of water?” (p. 121).³⁸ One study revealed that without knowledge on such topics, patients may possess lower self-confidence.⁷⁷ Other reasons patients sought knowledge were economic, legal, and otherwise practical in nature, for example, to aid advance care planning.

Patients who did not seek knowledge about their disease deferred their care to healthcare professionals, believed themselves incapable of understanding, were unaware they lacked knowledge, or were indifferent.^{36,44,45} Clark et al. found most patients deferred decision-making authority to their physicians and followed healthcare professionals’ advice for care rather than seeking to better understand HF and HF care.⁴⁵ As one patient stated: “I figure [clinician] knows what he’s talking about. . . because I don’t know anything about it” (p. 12).¹⁰⁵

Discussion

A synthesis of the findings across 73 diverse publications reporting qualitative findings about patients’ HF-related knowledge revealed the multidimensional nature of knowledge. Fig. 2 shows the primary insight from this study: that patient knowledge of HF, when considered in the context of patients’ lived experience, is a heterogeneous construct comprising at least five interacting components: content; development; application; communication; and patient experience. This finding offers a patient-centered perspective of HF knowledge that complements the clinical perspective of knowledge as a predictor of clinically relevant outcomes.^{4,107–109} The notion of knowledge as dynamic and contextual is consistent with depictions of knowledge in the cognitive science and naturalistic decision-making literatures.^{25–27} This implies that the model in Fig. 2 may be applicable to other domains of health-related knowledge, despite being developed from the HF literature. We next discuss several theoretical and practical implications of the derived model, also summarized in Fig. 2.

Patients’ disease-related knowledge may include misconceptions

From our synthesis, it was apparent that patients had a general understanding of their disease and self-management, yet also demonstrated misconceptions and partial understanding. These findings persist across studies, including those published in recent years,¹¹⁰ suggesting that knowledge deficits are ubiquitous and may be difficult to eliminate despite the popularity of educational efforts. Although studies in our review reported gaps in general HF knowledge, a review by Spaling et al. showed that such knowledge gaps may not affect self-care performance, which may be more influenced by patients’ strategies for living with HF.¹¹¹

Indeed, we found in this review that vague or partial knowledge about HF may not necessarily be harmful: for example, individuals may be adherent to medications even when they do not know each medication’s name or purpose.¹⁰² Similarly, a recent integrative literature review of 20 empirical studies of factors associated with self-care reported that knowledge of HF management was not strongly associated with self-care adherence.¹¹² Such findings suggest more investigation into when declarative knowledge matters and when it does not, especially in light of trials that have shown a positive effect of knowledge on self-care and care utilization outcomes.¹¹³

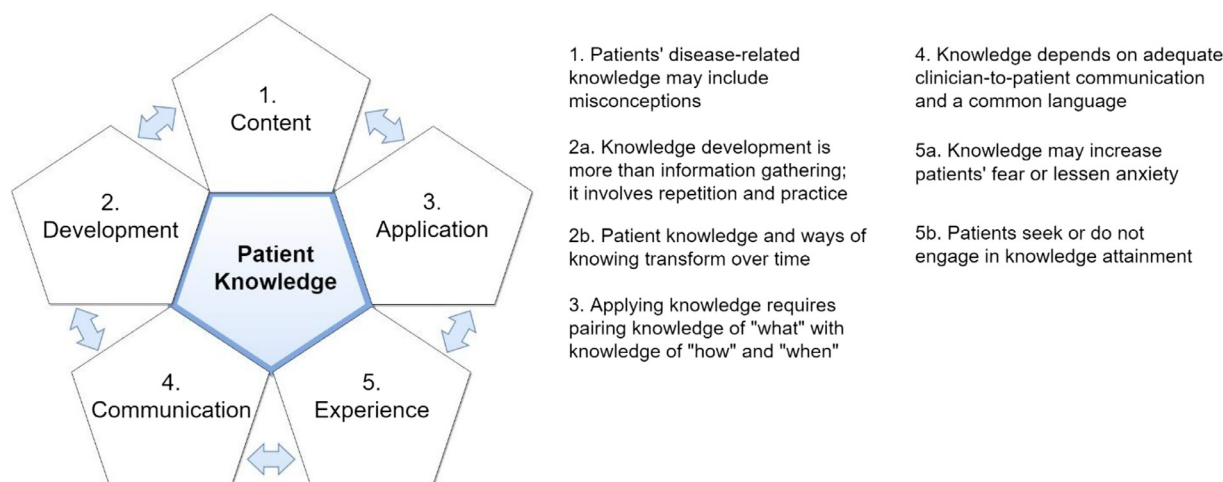


Fig. 2. Conceptual model of patient knowledge.

Knowledge development is more than information gathering, it involves repetition and practice

We found that patients receive HF-related information from various sources, often via written materials, but also directly from their clinicians, friends and family, and the Internet. This information is the basis of knowledge formation, which is supported by repetition and experience and evolves into skills such effective symptom recognition and decision making.^{114,115} The concept of transforming knowledge into skill through repetition and practice suggests that obtaining and maintaining HF-related information is the starting point for knowledge development, not the end goal. Support for this transformation can be provided through the use of simulation for training patients.¹¹⁶

Patient knowledge and ways of knowing transform over time

The findings in this review also show that patients' ways of knowing change, with the most reported example being that over time patients begin "listening" to their body and can detect subtle somatic cues. Accordingly, Riegel et al. proposed that interventions should focus on helping patients with HF identify and interpret symptoms through their somatic experience.¹¹⁷ Importantly, many skills and the ability to detect subtle somatic cues may not be captured by HF knowledge tests and may need to be assessed using newer techniques.¹¹⁸

Applying knowledge requires pairing knowledge of "what" with knowledge of "how" and "when"

While some patients are able to report what to do for self-management (restrict sodium), they may struggle with how to do it (eat fresh vegetables instead of canned). As above, the latter type of knowledge about "how" and "when" (as opposed to "what") may come with experience, skill development, and confidence. In a cross-sectional survey study of 139 patients with HF, more experienced patients recognized signs and symptoms and performed better at self-care than those who were newly diagnosed.¹¹⁹ Similarly, Riegel et al. reported that patients who were more confident in their self-care and had more experience managing HF had higher HF self-care performance scores.¹¹⁵ Our findings imply that patients may desire support for "how-to" knowledge as they are learning about their disease. This may be especially important knowledge for patients to gain as their HF severity increases.¹¹⁵

Knowledge depends on adequate clinician-to-patient communication and a common language

Our findings included the phenomenon of information not resulting in accurate knowledge, when the information was communicated by clinicians to patients who were hospitalized or not feeling well. We also found that patients may believe clinicians omit desired information. These findings corroborate another systematic review's findings that patients with HF perceive communication as poor and lacking.¹²⁰ Communication about HF knowledge going in the other direction, from patients to clinicians, was not described in the papers reviewed here and may be important to explore in future work.

Knowledge may increase patients' fear or lessen anxiety

In reviewed studies, some patients experienced fear related to knowledge, leading to avoiding knowledge and preferring to simply follow instructions. Avoiding information due to fear and anxiety could affect adherence to self-care. As van der Wal and colleagues stated: "patients can only comply when they possess some minimal level

of knowledge about the disease and the health care regimen" (p. 434–435).¹⁰⁹ Thus, there may be an outstanding need to support patients whose fear of knowing jeopardizes their ability to perform self-care and manage quality of life. In contrast, we also found that knowledge can alleviate anxiety for some patients by reducing uncertainty. It is worth further exploring how patients evaluate the potentially costly versus beneficial effects of knowledge.

Patients seek or do not engage in knowledge attainment

Patients' expectations, beliefs, and psychosocial factors may also affect patients' attitudes towards HF knowledge. Although our findings showed that some patients believed more knowledge was better and continued to gather information and ask questions, others appeared to view knowledge about their disease as essentially impossible to obtain because of clinical complexity and traditional patient-doctor roles. Additional work should investigate the relationships between attitudes towards knowledge and knowledge acquisition on one hand and on the other hand psychosocial factors, such as emotional state and mental health, cognitive ability, personality, and beliefs.¹²¹

Knowledge is a dynamic and integral component of living with chronic illness

This synthesis confirmed the premise that HF knowledge is dynamic and personal. It is shaped by subjective experience and evolves along with its possessor. This is not surprising given how HF has pervasive effects on individuals' lives yet is uniquely experienced by patients.^{19,108,114,120}

Implications

Several implications can be drawn from this synthesis of qualitative research on HF knowledge. First, to better understand the type of knowledge patients have, and their information gaps or misconceptions about HF, knowledge elicitation methods such as critical decision interviews could be used to draw out the information patients use to make decisions.¹²² These techniques complement cross-sectional assessments of knowledge-as-content. Other techniques can be used to assess the skill with which individuals apply knowledge.^{123,124}

Second, effective interventions could target both knowledge content and skills development. These interventions could include peer teaching and training from patients and family caregivers who have developed skills through repetition and experience.^{125,126} A systematic review reported that education may increase knowledge and improve some behaviors, but does not necessarily improve symptom recognition.¹²⁷ This supports complementing education with skills training and other methods for supporting patients' performance of tasks in context,^{78,128–131} also known as "patient work."¹³²

Third, the communication of information from clinician to patient involves sharing key information at the right time and in the right way. Research shows that educational interventions provided pre-discharge from the hospital, at discharge, or post-discharge show varying effectiveness,¹³³ and our findings suggest that how patients are feeling and whether they have looming questions, should be assessed before new information is shared. Communication involves establishing common language¹³⁴ and avoiding false presuppositions in the clinical dialogue.^{135,136} Thus, the nature of the interaction (e.g., time, place, emotional state, common goals, and language) is as important as the message itself, and should be the focus of future research. A specific avenue of future research is examining how metaphors can be, or already are, used by clinicians and patients to facilitate bidirectional HF knowledge communication.¹³⁷

Fourth, patients' experiences with HF knowledge attainment range from avoidance to intense knowledge seeking, as also seen in other research.¹³⁸ Thus, tools such as surveys or other assessments are necessary to understand the type and amount of knowledge preferred and necessary for the individual. Additional support should be provided as needed for psychological factors, such as depression and anxiety, which impact patient experiences with HF-related knowledge.¹³⁹

Fifth, the findings of this study have implications for the application of tools used in cross-sectional studies to measure explicit knowledge, such as the Atlanta Heart Failure Knowledge Test,¹²⁷ the Dutch Heart Failure Knowledge Scale,¹⁴⁰ and others.^{141–143} These instruments are largely used to assess what patients themselves know, whereas for some patients knowledge is distributed or delegated to family caregivers, clinicians, or may reside in cognitive artifacts (e.g., diaries, notes) rather than in internal memory alone.^{128–130} Our synthesis suggests that other measures are needed to understand the social and cognitive processes through which patients communicate, experience, and form knowledge.¹⁴⁴

Limitations and future directions

We did not formally organize analyses based on study characteristics such as method type, study quality, or patient population. The heterogeneity of studies also made it impractical to compare findings across groups such as race, gender, or national origin. Of the 73 articles reviewed, 22 papers (30%) contributed disproportionately to our findings, roughly assessed as studies that were cited four or more times in the results. We were limited to what was reported in original studies, and it is possible important aspects of knowledge were not well measured, underreported, or unreported. For example, the literature appeared to report knowledge failures more than knowledge successes, but it is not clear whether this was due to the true nature of knowledge in the population versus the research objectives or sampling methods of prior research. Narrative synthesis was well suited to our goal of producing a synthesized understanding of the nature of knowledge from qualitative studies. Additional work could complement such synthesis with review methods suited to the description and synthesis of quantitative studies, such as meta-analysis.

Unlike systematic reviews and other meta-analytic designs concerned with the evaluation of literature for effectiveness and rigor,¹⁴⁵ we did not perform an assessment of the quality of reviewed studies. The roles of others, e.g., how family caregivers participate in knowledge formation, were not explored in the findings for this synthesis and should be examined in future studies. Future work should apply and validate the model in Fig. 2 in qualitative, quantitative, or mixed method research on knowledge of patients with HF and other conditions. In particular, measures will need to be developed for each knowledge facet in the conceptual model.

Conclusion

Knowledge among patients with HF is more than a measure of what information can be obtained or retrieved at a given time. The construct of knowledge is complex, involving not only the content but also the dynamic nature by which knowledge is formed, applied, communicated, and experienced through the lens of a patient living with HF. This multidimensional model of patient knowledge-in-context calls for equally multidimensional research and intervention design.

Supplementary materials

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.hrting.2019.05.012>.

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