Patients Are Knowledge Workers in the Clinical Information Space

Elizabeth Lerner Papautsky[1] Emily S. Patterson[2]

[1] Department of Biomedical and Health Information Sciences, University of Illinois at Chicago, Chicago, Illinois, United States
[2] School of Health and Rehabilitation Sciences, The Ohio State University, Columbus, Ohio, United States

Address for correspondence Elizabeth Lerner Papautsky, PhD, Department of Biomedical and Health Information Sciences, College of Applied Health Sciences, 1919 West Taylor Street, Chicago, IL 60612, United States (e-mail: elp@uic.edu).

Appl Clin Inform 2021;12:133–140.

Abstract

Background Limited research exists on patient knowledge/cognition or "getting inside patients' heads." Because patients possess unique and privileged knowledge, clinicians need this information to make patient-centered and coordinated treatment planning decisions. To achieve patient-centered care, we characterize patient knowledge and contributions to the clinical information space.

Methods and Objectives In a theoretical overview, we explore the relevance of patient knowledge to care provision, apply historical perspectives of knowledge acquisition to patient knowledge, propose a representation of patient knowledge types across the continuum of care, and include illustrative vignettes about Mr. Jones. We highlight how the field of human factors (a core competency of health informatics) provides a perspective and methods for eliciting and characterizing patient knowledge.

Conclusion Patients play a vital role in the clinical information space by possessing and sharing unique knowledge relevant to the clinical picture. Without a patient's contributions, the clinical picture of the patient is incomplete. A human factors perspective informs patient-centered care and health information technology solutions to support clinical information sharing.

Keywords

- patient knowledge
- human factors
- health informatics
- patient-centered care
- knowledge
- cognition
- patient care

Background and Significance

There has recently been more research on characterizing patient behavior within and outside of clinical settings, mainly in the context of chronic or long-term illness, to inform the development of human-centered technologies. Patient ergonomics, a subdiscipline of human factors, studies the health-related work of patients, caregivers, and community members.[1] Limited research has been concerned with "getting inside patients' heads" or patient cognition. Cognition refers to the processes (associated with knowledge, thinking, memory, attention) underlying outward behaviors. Patients possess unique and privileged knowledge particularly about historical and daily experiences with their illness. Although clinicians need this information from patients to provide patient-centered care, patient knowledge may not be systematically elicited or documented by clinicians. In this article, we propose a theoretical characterization of patient knowledge and explore its relevance to care provision by applying traditional cognitive science and human factors (a core competency of health informatics[2]) perspectives to define patients as knowledge workers across the continuum of care. To demonstrate that patients possess and share knowledge relevant to the clinical picture, we present vignettes about Mr. Jones.

- *Background—A patient has experience and comprehension of illness, medication side effects, and self-care management strategies*: Mr. Jones, a 50-year-old male with a

received
August 5, 2020
accepted after revision
December 4, 2020

© 2021. Thieme. All rights reserved.
Georg Thieme Verlag KG,
Rüdigerstraße 14,
70469 Stuttgart, Germany

DOI https://doi.org/10.1055/s-0041-1723022.
ISSN 1869-0327.

This document was downloaded for personal use only. Unauthorized distribution is strictly prohibited.

master's degree, was diagnosed with multiple myeloma 4 years ago. Mr. Jones also suffers from hypertension, for which he takes blood pressure medication and exercises regularly. Mr. Jones' cancer has relapsed multiple times but it has been controlled with chemotherapy and stem cell replacement. He regularly sees his oncologist and his primary care provider. Since his diagnosis, Mr. Jones has had several emergency room visits and hospitalizations at both his local hospital and the academic medical center where he gets his cancer care. With the help of his wife, Mr. Jones manages the logistics of his doctors' visits and chemotherapy infusions, as well as medications and self-care activities. He keeps his test results in a binder and adjusts lifestyle and activity levels according to his oncologist's guidance and personal strategies. Recently, Mr. Jones has begun to suffer from debilitating neuropathy caused by one of his cancer medications. He also had a stairlift installed in his home to prevent falls due to fatigue and lightheadedness. Mr. Jones has an informed understanding of his condition and the mechanisms of action of his medications. He has also developed strategies for managing his life, given medication side effects.

- *Patient and caregiver communication of patient status may impact care safety and quality*: While neutropenic due to chemotherapy, Mr. Jones had an acute event that lands him in the local hospital's emergency room, rather than the academic medical center where he receives his cancer care. The electronic health record (EHR) systems are not integrated. The emergency room clinicians do not follow guidelines for neutropenic precautions and prepare to conduct a series of unnecessary tests. Mr. Jones highlights his immunocompromised status to the clinicians and asks his wife to provide blood test results from the previous day. Clinicians put in place neutropenic precautions.
- *Strategically withholding patient knowledge may impact decision making regarding treatment options*: Mr. Jones is eligible for a clinical trial for a promising new medication. Mr. Jones sees this clinical trial as his last hope and strategically withholds from his care team the poor quality of life that he is experiencing at home for fear of not being included.
- *Experiences of medication side effects may impact medication options*: Mr. Jones is interested in exploring a new hypertension medication. When asked by his primary care physician about bothersome side effects of his cancer medications, Mr. Jones forgets to mention neuropathy. Mr. Jones is thus prescribed a medication that exacerbates his neuropathy, thus impacting his quality of life as well as his functionality.

Despite the impetus toward patient–clinician teaming in health care and policy for systematic sharing of patient-generated health data,[3] research to characterize patient cognition as underlying their contributions to the clinical information space is limited. This is a challenge for both technology development and synchronous and asynchronous communication. The content of patient knowledge informs thinking and underlies behaviors of managing wellness, health, and interfacing with the health care system. Qualitative researchers like nurse and sociologist, Corbin and Strauss have a history of capturing patient experiences with chronic illness and characterizing activities of self-care management as "work."[4] However, rather than answering research and applied questions of how to support the work, their research objective was the discovery of patient experiences of work. Designing human-centered health information technologies (HITs) to support capturing, sharing, and integrating of patient-held knowledge requires the understanding of not only what patients do, but when, why, and how they do it.

Human factors approaches[5–7] have been used to characterize decision making of professional experts in real-world domains of aviation, nuclear power, military, and health care. Findings have informed models of knowledge acquisition and decision making.[8–10] Only recently have patients become recognized as active participants and decision makers in and outside of the health care system.[11] Despite the relevance of cognitive science and human factors literature to this applied problem space, most theory and research on patient cognition have stopped short of applying it.

Why Is Patient Knowledge Relevant?

Patient knowledge is relevant because of its relationship with clinical outcomes. For instance, research by Khan et al in pediatric hospital settings highlights that families play a role in patient safety through vigilance and reporting of potential errors.[12,13] Cognitive processes associated with decision making underlie vigilance and reporting. Work by Weiner and Schwartz[14] spanning the last decade stresses the importance of avoiding contextual mistakes in medical decision making by physicians asking the "right" questions of patients. By gathering contextual information from patients, particularly about life and social constraints, physicians can better inform patient-centered treatment plans, highlighting the value of patient contributions. This work is an example of the importance of clinician-driven knowledge elicitation from patients.

Further, lower health literacy is associated with lower rates of preventative care, medication management challenges, more hospitalizations, more emergency care use, poorer health, and higher mortality rates.[15–17] On the other hand, patients and caregivers with higher health literacy may actively influence their care plans through engagement and shared decision making.[18] In a *BMJ Comment*, Kennedy highlights the idea that patients are experts in their "experience, feelings, fears, hopes, and desires."[19] Thus, even in the absence of illness-specific knowledge, patients may be experts in their own right. The term "expert patient" refers to patients who are not just health care consumers but *producers of health* through deep knowledge and comprehension.[20–24] The use of this terminology highlights the applicability of traditional approaches of studying expertise to patients.

Cognitive Science Perspectives on Knowledge Acquisition

Traditionally, cognitive scientists have examined the acquisition of knowledge in service of education. In 1980, Dreyfus and Dreyfus proposed a stage model of knowledge

 © 2021. Thieme. All rights reserved.

This document was downloaded for personal use only. Unauthorized distribution is strictly prohibited.

acquisition where a learner progresses from a rule-bound novice to an intuitive reasoner making decisions based on tacit knowledge.[9] Generalized to nursing practice,[25] the Dreyfus model continues to be heavily cited in medicine today. In addressing designing medical education to support knowledge acquisition, Ericsson's deliberate practice theory is widely accepted. This theory's idea is that expert performance is a function of intentional practice designed by educators. This practice incorporates opportunities for problem solving, immediate feedback, evaluation, and repeat performance.[26] Ericsson's theory has been generalized to other professional domains such as transportation, entrepreneurial skills, writing, teaching, and even music, chess, drawing, math, and software design.[27]

In complement, human factors scientists have been seeking to understand knowledge through theoretical perspectives such as naturalistic decision making (NDM) that accounts for expert performance in complex real-world domains.[6] NDM provides both a theoretical perspective and a set of research tools to examine how professionals (primarily subject matter experts or SMEs) solve problems, make decisions, and perform cognitively and perceptually complex work. This work has traditionally been conducted in domains marked by uncertainty, time limitations, and high consequences for erroneous actions. Because it is not feasible to bring real-world complexity into the laboratory, methods include interviews to elicit challenging lived incidents from SMEs and identify and unpack decision points. Again, much of this research has been focused on professional domains to capture expertise and deliver it to novices as part of training, education, and decision support solutions. In health care, substantial literature exists using the NDM perspective to characterize clinicians' knowledge and decision making.[28–31] However, again, the topic of patient cognition has received little attention even in human factors.

Of particular relevance to informatics is the understanding that many types of patient knowledge, especially in the cases of chronic and long-term illness, are not acquired in a deliberate manner through formal education and training, but are emergent as a function of experience and continuity across time and space of the care continuum. Some types of patient knowledge may be acquired through implicit learning or learning that occurs without conscious effort,[32] and may potentially yield deep understanding. Although authors suggest that self-management of chronic illness like diabetes "draws on the same cognitive skills found in experts from diverse professional domains,"[33] few studies have focused on examining the acquisition and content of such knowledge. For instance, Lippa et al[33] suggest that patient's problem detection skills and strategies acquired through practice in diabetes self-management are associated with better adherence and greater glycemic control, which may indicate proficient performance. Recently, Holden et al[34] used the NDM approach of incident-based interviews to characterize decision making personas to inform the design of solutions to support patients with heart failure. Their study highlights the need to understand cognitive processes, which are associated with decision making to inform human-centered design.

Traditionally, there are two types of knowledge, explicit and tacit. Explicit (e.g., declarative, expressive) knowledge can be easily articulated, codified, and transferred to others. For example, explicit knowledge may be acquired through book learning. In contrast, tacit (e.g., implicit), proposed by Polanyi,[35] is acquired through practical, lived experience, and often cannot be readily articulated. Knowledge associated with carrying out skills or tasks (e.g., riding a bike, tying shoelaces) is termed procedural knowledge and is considered implicit. Although there are some slight variations in the literature regarding terminology and distinctions, we emphasize that a substantial literature exists in cognitive science and propose the need to extend and adapt accordingly to examine and characterize patient knowledge. Further, patients possess and manage knowledge that falls under the theoretically accepted categories of knowledge of explicit, tacit, and procedural and additional categories of privileged knowledge or "knowledge in the head," such as preferences and history. Privileged patient knowledge that is unelicited due to barriers (e.g., time constraints, individual differences, bias) will remain so.

Patient Is a Knowledge Worker

Holden et al[11] positioned the patient, alongside the clinicians, at the center of the health care complex sociotechnical system in SEIPS 2.0. The authors highlight that the patient conducts "work" ranging from logistical planning and execution to medication to self-care management, even in cases where there is no disease present. The SEIPS 2.0 framework highlights an active patient role across patient-only activities as well as patient–clinician teaming. A body of literature now exists examining patient work[36–39] focused on understanding daily contexts and activities, culminating in the idea that investigating health care workflow is incomplete without capturing patients' health-related activities in clinical and daily-living settings.[40] As a function of these activities, patients possess, manage, apply, create, and share knowledge. A recent review of qualitative literature on heart failure proposes a characterization of patient knowledge based on content, development, application, communication, and experience, highlighting that patient knowledge is implicit, explicit, and dynamic.[41] Through such work, patients are *knowledge workers*. A knowledge worker is a term that has been traditionally applied to professionals who conduct thinking and reasoning as part of their work.[42,43]

What Knowledge Do Patients Possess?

Bodenheimer et al[44] summarized one role of patient knowledge during the self-management of chronic diseases in primary care. They highlight the importance of patients knowing how to identify their problems from their perspective, take actions to address these problems, and adapt as circumstances change. However, only a few[45] studies investigate how a patient acquires such knowledge in the context of a complex illness marked by a particular trajectory, and how that unfolds across time and settings. Recently introduced SEIPS 3.0 highlights the concept of the patient journey across space and time, with patient knowledge playing a role in processes and outcomes.[46]

 © 2021. Thieme. All rights reserved.

This document was downloaded for personal use only. Unauthorized distribution is strictly prohibited.

Table 1 Overview of patient knowledge based on cognitive science knowledge types

Cognitive science knowledge types	Description	Patient examples of knowledge application
Explicit[71]	Readily codified, accessed, and verbalized	Articulation of medication and treatment protocols, and logistics of interactions with health care system
Tacit, implicit, intuitive[71]	Not codified, not easily expressed or transferred	Judgment and decision making regarding situation awareness, physical and psychological baseline, change perceptions, phenomenology of symptoms, etc
Procedural[72]	Task performance	Processes and strategies for self-care management, wound care, medication administration, etc

Given that no taxonomy of patient knowledge exists, we propose first to apply theoretically accepted categories of knowledge of explicit, tacit, and procedural to patient knowledge, as shown in ►Table 1. ►Table 1 contains cognitive science knowledge types and their descriptions, along with examples. Two observations emerge: (1) multiple knowledge examples belong in the tacit category, suggesting that patients may have trouble articulating them, and (2) there are additional knowledge examples that potentially do not fit in this framework.

Thus, we propose additional knowledge examples. We refer to these examples as *patient factors* (both static and dynamic), an all-encompassing term that refers to patients' privileged knowledge. The examples of patient factors represented in ►Fig. 1 may be privileged to the patient—some (e.g., attributes) may be more systematically captured and potentially documented in the EHR. Still, most do not even have designated fields in the EHR. These patient factors both inform and are a function of the patient journey across the care continuum and may also evolve (e.g., preferences) as a function of time and experience. ►Fig. 1 represents the problem space of patient knowledge that is in particular need of research attention.

Acquisition of Knowledge

A crucial mechanism that accounts for privileged patient knowledge is experience and continuity. Patients (and caregivers) are the only ones with continuity across the care continuum—time, space (home, clinical settings, contexts of daily living), and multiple clinicians. ►Fig. 2 represents the patient care continuum as a *spaghetti junction*—a term used to describe a complex traffic interchange.[47] Not unlike the spaghetti junction, the patient journey (along with caregivers and primarily in the home) across the care continuum is characterized by a winding path with a variety of barriers (construction), highs and lows in physical and mental health (under- and overpasses), the potential for guidance from lay and clinical caregivers such as nurse navigators (a Global Positioning System), and interactions with the health care system requiring planning, logistics, and information exchange (exits off the highway). We note that health care interactions comprise a fraction of time and space within the full patient journey. We currently have no measures to account for patient continuity, and indeed, it is not explicitly represented in the EHR.

Patients may also acquire knowledge across the patient journey via formal or deliberate mechanisms. Through patient

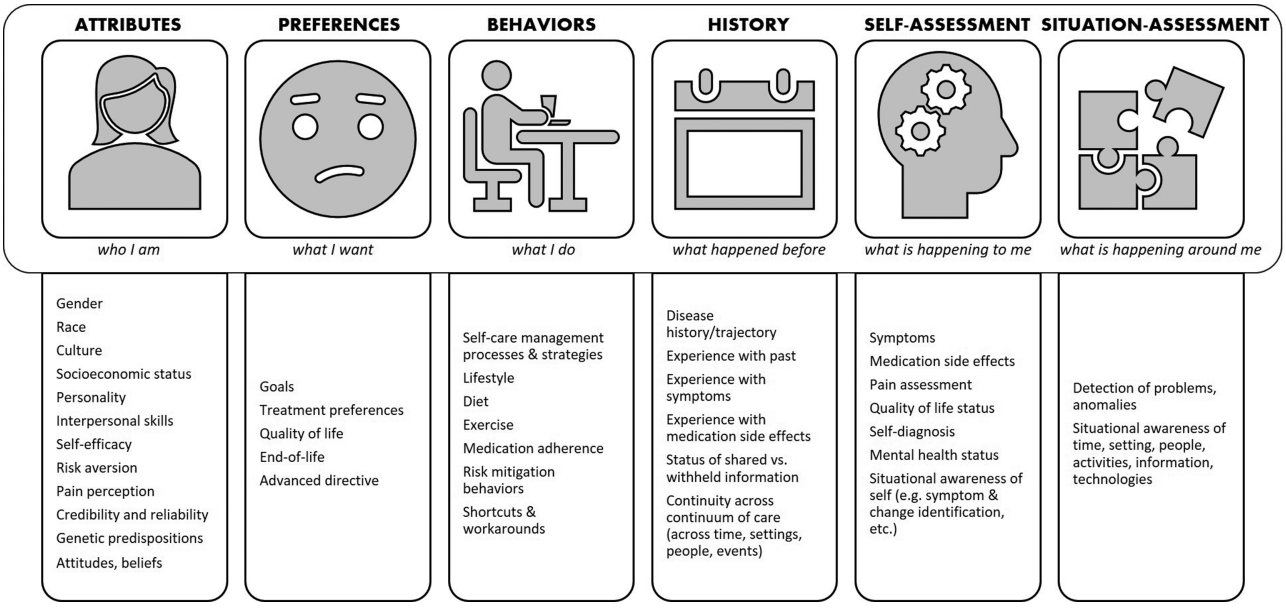


Fig. 1 Overview of patient factors.

 © 2021. Thieme. All rights reserved.

This document was downloaded for personal use only. Unauthorized distribution is strictly prohibited.

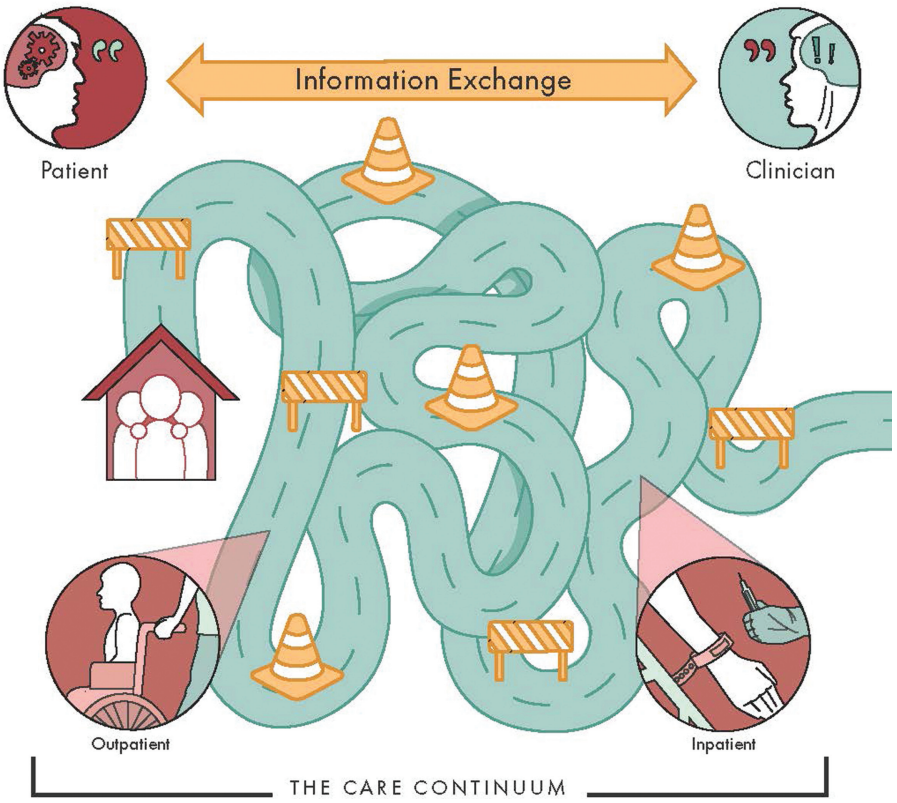


Fig. 2 The patient is the only one that has continuity across the entire care continuum marked by time, settings (clinical, as well as contexts of daily living), and clinicians. (2018, Alexandria Cook)

education, the health care system focuses on providing patients with tools to support empowerment (understanding the health care system and engaging in behaviors that influence situations and outcomes)[48] and engagement.[49] Numerous examples exist, including: American Cancer Society[50] provides patient educational resources specific to each cancer type, as does American Heart Association,[51] on hypertension. Individual organizations, offices, clinics, and clinicians may provide additional patient education. A growing body of literature exists on the acceptance of consumer HITs.[52] Human-centered consumer HIT can provide opportunities for managing, storing, and sharing health information (e.g., heart rate, blood glucose monitoring, etc.) and learning about self-care management. Yet, nondeliberately or implicitly acquired knowledge continues to remain poorly understood. Brown and Duguid's organizational knowledge acquisition[53] theory, focusing on informal and fluid knowledge acquisition, calls for a focus on practice or application. It also highlights the value of communities in learning. Online patient communities that serve not just as spaces for support, but spaces for information exchange (assuming moderators filter unreliable information), come to mind.

Implications: Applying Patient Knowledge to the Clinical Information Space and Research

Patients are responsible for navigating an increasingly complex health care system with information distributed across numerous clinicians and staff, technologies, paper artifacts, and physical settings. Further, through privileged knowledge (phenomenology of symptoms, case history), patients may be the drivers of their care, as suggested by multiple sclerosis research.[18] Some examples of ways in which patients drive their care include making decisions within and outside of their relationships with clinicians. Traditionally, when we talk about patient decision making, it is often focused on selecting treatment options as a function of patient–clinician interactions and the disease context. However, patients make other decisions that receive less research attention, which may or may not play a role in their outcomes. The following are just some examples of decisions that patients routinely engage in independently (or in concert with their nonclinical caregivers): self-detecting difference in health status,[54] seeking medical care (when, how, from whom, etc.),[18] managing medications,[55] releasing privileged information strategically,[18] self-medicating with over-the-counter medicines and self-treating,[44,56] and requesting and receiving preventative care (seeking, etc.).[57,58] No matter the level of knowledge, patients are decision makers.

In this article, we highlighted the clinical value of patient knowledge. We recognize the unprecedented complexity of studying and characterizing patient cognition and behavior, given they are "situated" within complex sociotechnical systems. Understanding patient cognition or the *whys* behind patient behaviors can support (1) the design of human-centered technologies for patient–clinician synchronous and asynchronous information sharing, (2) patient–clinician teaming in decision making, (3) informed and engaged patient navigation of the care continuum, and (4) patient assessment

 © 2021. Thieme. All rights reserved.

This document was downloaded for personal use only. Unauthorized distribution is strictly prohibited.

and adoption of information, resources, and tools for self-management of health and wellness.

To make the above a reality, patients need to take part in the research process. There is no question that researchers have embraced the necessity of including patients to generate and evaluate patient-facing solutions. Some examples include patient evaluation of an application to support self-care during gastrointestinal cancer,[59] language for medication instructions,[60] and information web sites.[61] A study to train patients to create a continuity of care document to share with clinicians across systems reduced duplication of laboratory tests.[62] Further, Riggare[63] writes about the need for and the value of persons with lived experiences with illness engaging in research. Twitter stakeholder communities, including patients and clinicians, such as #BTSM (brain tumor social media)[64] and #BCSM (breast cancer social media),[65] (among numerous other benefits) inform research ranging from bringing together ad hoc collaborations and developing research and operational questions, to disseminating research findings, not to mention serving as research mechanisms. Last but not least, using the term "patients marshaled epistemic authority," a recent publication highlights how it is patients, through social media, that shed research attention on "long-haul Covid."[66] In addition, a 2020 panel at the Human Factors in Health Care Symposium highlighted the unique contributions of researchers bringing their patient perspectives to research.[67] Ultimately, engaging patients as partners across the research, development, and implementation process is key to designing solutions that account for patient knowledge.

Takeaways

Patient knowledge is integral to inform patient–clinician teaming. Currently, a research gap exists on both sides of the information exchange equation between patients and clinicians. We presented a theoretical characterization of patient knowledge's problem space as critical to informing patient-centered care. Future research needs to address the application and integration of patient knowledge as part of patient–clinician teaming and decision making.

In the absence of theory applied to informatics solutions, we may mistakenly assume that external behavior reflects an accurate understanding. However, there lies a potential disconnect. Studying cognition can help identify gaps and inaccuracies in understanding, thereby informing appropriately tailored informatics solutions. The study by Lippa and Klein on patient cognition of diabetes self-care is an example of such research.[68] There is much work to be done—examining specific illnesses, settings, and patient life contexts. We leave the reader with the following takeaways:

- *Patients are knowledge workers.* Patients possess unique knowledge that clinicians need. By defining the patient as a knowledge worker, we can begin to develop a much-needed taxonomy to inform both research and practice.
- *Patient knowledge impacts clinical outcomes.* Patient-held knowledge is clinically relevant, stressing the importance of developing solutions to facilitate patient knowledge sharing and integration.
- *The field of human factors offers a perspective and approaches for characterizing and eliciting the content of patient knowledge.* Based on decades of examining cognition and behavior, the field of human factors has approaches such as cognitive task analysis (CTA) applicable to characterizing patient cognition, as demonstrated by studies by Lippa et al[18,69] and Holden et al.[34] Further, literature has highlighted the complementary nature of CTA and participatory design.[42]
- *Engaging patients as partners in research is needed.* The active participation of the general public (e.g., patients, citizens, etc.) as partners in the research process (a shift toward citizen science) is key to developing solutions that effectively account for patient knowledge.[70]

Clinical Relevance Statement

The clinical picture is incomplete without privileged and unique knowledge from patients about their health, particularly for complex or chronic illness. Understanding patient knowledge is necessary to inform patient- and provider-centered HIT solutions to support information sharing and integration.

Multiple Choice Questions

1. Patient knowledge is clinically relevant because:
   a. Patients may possess unique and privileged information.
   b. Patients may have historical information regarding their illness.
   c. Patients may be the only constant across the continuum of care.
   d. All of the above.

   Correct Answer: The correct answer is option d.
2. Cognitive science can offer theoretical perspectives to studying patient knowledge because:
   a. Cognitive scientists primarily conduct laboratory research.
   b. Cognitive scientists have long studied knowledge acquisition.
   c. It focuses on human behavior.
   d. It has long focused on patient cognition in real-world settings.

   Correct Answer: The correct answer is option b.

Protection of Human and Animal Subjects

No human subjects were involved in this study.

Funding

This study was not funded.

Conflict of Interest

None declared.

 © 2021. Thieme. All rights reserved.

This document was downloaded for personal use only. Unauthorized distribution is strictly prohibited.

Acknowledgments

We are grateful to Alexandria Cook, BFA, MS (Biomedical Visualization, Department of Biomedical and Health Information Sciences, University of Illinois at Chicago) for coming up with the term "spaghetti junction" as an analogy for the care continuum and for developing ►Fig. 2.

References

1 Holden RJ, Cornet VP, Valdez RS. Patient ergonomics: 10-year mapping review of patient-centered human factors. Appl Ergon 2020;82:102972
2 Valenta AL, Berner ES, Boren SA, et al. AMIA Board white paper: AMIA 2017 core competencies for applied health informatics education at the master's degree level. J Am Med Inform Assoc 2018;25(12):1657–1668
3 HealthIT.gov. Patient-generated health data. Published March 21, 2018. Accessed October 22, 2020 at: https://www.healthit.gov/topic/scientific-initiatives/patient-generated-health-data
4 Corbin J, Strauss A. Managing chronic illness at home: three lines of work. Qual Sociol 1985;8(03):224–247
5 Hollnagel E, Woods DD. Joint Cognitive Systems: Patterns in Cognitive Systems Engineering. Boca Raton, FL: CRC Press; 2006
6 Klein G. Naturalistic decision making. Hum Factors 2008;50(03):456–460
7 Klein GA. A Recognition-Primed Decision (RPD) Model of Rapid Decision Making. New York, NYAblex Publishing Corporation1993. Accessed May 26, 2017 at: https://pdfs.semanticscholar.org/0672/092ecc507fb41d81e82d2986cf86c4bff14f.pdf
8 Benner P. From novice to expert. Menlo Park . Published online 1984. Accessed December 31, 2020 at: http://files.eric.ed.gov/fulltext/ED384695.pdf#page=130
9 Dreyfus SE, Dreyfus HL. A five-stage model of the mental activities involved in directed skill acquisition. California Univ Berkeley Operations Research Center, DTIC Document. Available at: https://apps.dtic.mil/dtic/tr/fulltext/u2/a084551.pdf
10 Ericsson KA, Krampe RT, Tesch-Römer C. The role of deliberate practice in the acquisition of expert performance. Psychol Rev 1993;100(03):363–406
11 Holden RJ, Carayon P, Gurses AP, et al. SEIPS 2.0: a human factors framework for studying and improving the work of healthcare professionals and patients. Ergonomics 2013;56(11):1669–1686
12 Khan A, Coffey M, Litterer KP, et al;the Patient and Family Centered I-PASS Study Group. Families as partners in hospital error and adverse event surveillance. JAMA Pediatr 2017;171(04):372–381
13 Khan A, Furtak SL, Melvin P, Rogers JE, Schuster MA, Landrigan CP. Parent-reported errors and adverse events in hospitalized children. JAMA Pediatr 2016;170(04):e154608–e154608
14 Weiner SJ, Schwartz A. Contextual errors in medical decision making: overlooked and understudied. Acad Med 2016;91(05):657–662
15 Easton P, Entwistle VA, Williams B. Health in the 'hidden population' of people with low literacy. A systematic review of the literature. BMC Public Health 2010;10:459
16 Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med 2011;155(02):97–107
17 McDonald M, Shenkman L. Health literacy and health outcomes of adults in the United States: implications for providers. Internet J Allied Health Sci Pract 2018;16(04)
18 Lippa KD, Feufel MA, Robinson FE, Shalin VL. Navigating the decision space: shared medical decision making as distributed cognition. Qual Health Res 2017;27(07):1035–1048
19 Kennedy I. Patients are experts in their own field. BMJ 2003;326(7402):1276–1277
20 Boulet LP. The expert patient and chronic respiratory diseases. Can Respir J 2016;2016:9454506
21 Expert Patient. A New Approach to Chronic Disease Management for the 21st Century London: DoH; 2001
22 Lorig K. Partnerships between expert patients and physicians. Lancet 2002;359(9309):814–815
23 Shaw J, Baker M. "Expert patient"—dream or nightmare? BMJ 2004;328(7442):723–724
24 Tattersall RL. The expert patient: a new approach to chronic disease management for the twenty-first century. Clin Med (Lond) 2002;2(03):227–229
25 Benner P. Using the Dreyfus model of skill acquisition to describe and interpret skill acquisition and clinical judgment in nursing practice and education. Bull Sci Technol Soc 2004;24(03):188–199
26 Ericsson KA. Deliberate practice and acquisition of expert performance: a general overview. Acad Emerg Med 2008;15(11):988–994
27 Ericsson KA, Hoffman RR, Kozbelt A, Williams AM. The Cambridge Handbook of Expertise and Expert Performance. Cambridge: Cambridge University Press; 2018
28 Militello LG, Anders S, Downs SM, et al. Understanding how primary care clinicians make sense of chronic pain. Cogn Technol Work 2018;20(04):575–584
29 Militello LG, Diiulio JB, Borders MR, et al. Evaluating a modular decision support application for colorectal cancer screening. Appl Clin Inform 2017;8(01):162–179
30 Militello LG, Rattray NA, Flanagan ME, et al. "Workin' on our night moves": how residents prepare for shift handoffs. Jt Comm J Qual Patient Saf 2018;44(08):485–493
31 Militello LG, Savoy A, Porter B, et al. Hidden complexities in information flow between primary and specialty care clinics. Cogn Technol Work 2018;20(04):565–574
32 Reber AS. Implicit learning and tacit knowledge. J Exp Psychol Gen 1989;118(03):219
33 Lippa KD, Klein HA, Shalin VL. Everyday expertise: cognitive demands in diabetes self-management. Hum Factors 2008;50(01):112–120
34 Holden RJ, Daley CN, Mickelson RS, et al. Patient decision-making personas: an application of a patient-centered cognitive task analysis (P-CTA). Appl Ergon 2020;87:103107
35 Polanyi M. The logic of tacit inference. Philosophy 1966;41(155):1–18
36 Holden RJ, Schubert CC, Mickelson RS. The patient work system: an analysis of self-care performance barriers among elderly heart failure patients and their informal caregivers. Appl Ergon 2015;47:133–150
37 Holden RJ, Valdez RS, Schubert CC, Thompson MJ, Hundt AS. Macroergonomic factors in the patient work system: examining the context of patients with chronic illness. Ergonomics 2017;60(01):26–43
38 Valdez RS, Holden RJ, Novak LL, Veinot TC. Transforming consumer health informatics through a patient work framework: connecting patients to context. J Am Med Inform Assoc 2015;22(01):2–10
39 Valdez RS, Holden RJ, Novak LL, Veinot TC. Technical infrastructure implications of the patient work framework. J Am Med Inform Assoc 2015;22(e1):e213–e215
40 Ozkaynak M, Valdez R, Holden RJ, Weiss J. Infinicare framework for integrated understanding of health-related activities in clinical and daily-living contexts. Health Syst (Basingstoke) 2017;7(01):66–78
41 Daley C, Al-Abdulmunem M, Holden RJ. Knowledge among patients with heart failure: A narrative synthesis of qualitative research. Heart Lung 2019;48(06):477–485
42 Drucker PF. The Landmarks of Tomorrow: On Economic and Social Progress in the Twentieth-Century. Portsmouth, NH: Heinemann; 1959
43 Sanders EB-N. Information, inspiration and co-creation. Paper presented at: Proceedings of the 6th International Conference of

 © 2021. Thieme. All rights reserved.

This document was downloaded for personal use only. Unauthorized distribution is strictly prohibited.

the European Academy of Design. University of the Arts Bremen, Germany; March 29–31, 2005
44 Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. JAMA 2002;288 (19):2469–2475
45 Pollack AH, Backonja U, Miller AD, et al. Closing the gap: Supporting patients' transition to self-management after hospitalization. Proc SIGCHI Conf Hum Factor Comput Syst 2016:5324–5336
46 Carayon P, Wooldridge A, Hoonakker P, Hundt AS, Kelly MM. SEIPS 3.0: Human-centered design of the patient journey for patient safety. Appl Ergon 2020;84:103033
47 Collins English Dictionary. Spaghetti junction definition and meaning 2020. Accessed October 23, 2020 at: https://www.collinsdictionary.com/us/dictionary/english/spaghetti-junction
48 Eskildsen NB, Joergensen CR, Thomsen TG, et al. Patient empowerment: a systematic review of questionnaires measuring empowerment in cancer patients. Acta Oncol 2017;56(02):156–165
49 Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. BMJ 2007;335(7609):24–27
50 American Cancer Society. Learn about cancer. Published 2018. Accessed July 2, 2018 at: https://www.cancer.org/cancer.html
51 American Heart Association. High blood pressure. Published 2021. Accessed January 21, 2021 at: https://www.heart.org/en/health-topics/high-blood-pressure
52 Or CKL, Karsh B-T. A systematic review of patient acceptance of consumer health information technology. J Am Med Inform Assoc 2009;16(04):550–560
53 Brown JS, Duguid P. Knowledge and organization: a social-practice perspective. Organ Sci 2001;12(02):198–213
54 Sindrilaru A, Neckermann V, Eigentler T, et al. Self-detection frequency and recognition patterns in medium to high-risk cutaneous melanoma patients. J Dtsch Dermatol Ges 2017;15(01):61–67
55 Polinski JM, Kesselheim AS, Frolkis JP, Wescott P, Allen-Coleman C, Fischer MA. A matter of trust: patient barriers to primary medication adherence. Health Educ Res 2014;29(05):755–763
56 Blenkinsopp A, Bradley C. Patients, society, and the increase in self medication. BMJ 1996;312(7031):629–632
57 Katz D, Tengekyon AJ, Kahan NR, Calderon-Margalit R. Patient and physician characteristics affect adherence to screening mammography: a population-based cohort study. PLoS One 2018;13(03): e0194409
58 Lee Y, Aurshina A, Lee AJ, et al. Routine colonoscopy, diabetic eye care, mammogram and pap smear screening in vascular surgery patients. Vascular 2018;26(04):372–377
59 Berry DL, Blonquist TM, Nayak MM, Grenon N, Momani TG, McCleary NJ. Self-care support for patients with gastrointestinal cancer: iCancerHealth. Appl Clin Inform 2018;9(04): 833–840
60 Ancker JS, Send A, Hafeez B, Osorio SN, Abramson E. Health IT usability focus section: adapting EHR-based medication instructions to comply with plain language guidance-a randomized experiment. Appl Clin Inform 2017;8(04):1127–1143
61 Peute LW, Knijnenburg SL, Kremer LC, Jaspers MWM. A concise and practical framework for the development and usability evaluation of patient information websites. Appl Clin Inform 2015;6(02):383–399
62 Turvey CL, Klein DM, Witry M, et al. Patient education for consumer-mediated HIE: a pilot randomized controlled trial of the department of veterans affairs Blue Button. Appl Clin Inform 2016;7(03):765–776
63 Riggare S. Patient researchers - the missing link? Nat Med 2020; 26(10):1507–1507
64 Feliciano JT, Salmi L, Blotner C, et al. Brain tumor discussions on Twitter (#BTSM): social network analysis. J Med Internet Res 2020;22(10):e22005
65 Katz MS, Staley AC, Attai DJ. A history of #BCSM and insights for patient-centered online interaction and engagement. J Patient Cent Res Rev 2020;7(04):304–312
66 Callard F, Perego E. How and why patients made Long Covid. Soc Sci Med 2020:113426
67 Papautsky EL, Holden RJ, Valdez RS, Ernst K, Kushniruk A. The patient in patient safety: unique perspectives of researchers who are also patients. In: Proceedings of the International Symposium on Human Factors and Ergonomics in Health Care. Vol 9. Los Angeles, CASAGE Publications2020:292–296
68 Lippa KD, Klein HA. Portraits of patient cognition: how patients understand diabetes self-care. Can J Nurs Res 2008;40(03): 80–95
69 Lippa KD, Klein HA, Shalin VL. Everyday expertise: cognitive demands in diabetes selfmanagement. Hum Factors 2008;50 (01):112–120
70 Petersen C, Austin RR, Backonja U, et al. Citizen science to further precision medicine: from vision to implementation. JAMIA Open 2019;3(01):2–8
71 Polanyi M. Personal Knowledge: Towards a Post-Critical Philosophy. Chicago, IL: University of Chicago Press; 1958
72 Glaser R. Education and thinking: the role of knowledge. Am Psychol 1984;39(02):93–104

This document was downloaded for personal use only. Unauthorized distribution is strictly prohibited.