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ORIGINAL RESEARCH

How Can eHealth Technology Address Challenges Related to Multimorbidity? Perspectives from Patients with Multiple Chronic Conditions

Donna M. Zulman, M.D., M.S.[1,2]*, Emily C. Jenchura, B.S.*[3]*, Danielle M. Cohen, M.P.H.*[2]*,*
Eleanor T. Lewis, Ph.D.[1]*, Thomas K. Houston, M.D.*[4,5]*, and Steven M. Asch, M.D., M.P.H.*[1,2]

[1]Center for Innovation to Implementation (Ci2i), VA Palo Alto Health Care System, Menlo Park, CA, USA; [2]Division of General Medical Disciplines, Stanford University, Stanford, CA, USA; [3]Department of Psychology, Arizona State University, Tempe, AZ, USA; [4]eHealth Quality Enhancement Research Initiative, Bedford VA Medical Center, Bedford, MA, USA; [5]Division of Health Informatics and Implementation Science, University of Massachusetts Medical School, Worcester, MA, USA.

BACKGROUND: Patient eHealth technology offers potential support for disease self-management, but the value of existing applications for patients with multiple chronic conditions (MCCs) is unclear.

OBJECTIVES: To understand self-management and health care navigation challenges that patients face due to MCCs and to identify opportunities to support these patients through new and enhanced eHealth technology.

DESIGN: After administering a screening survey, we conducted 10 focus groups of 3–8 patients grouped by age, sex, and common chronic conditions. Patients discussed challenges associated with having MCCs and their use of (and desires from) technology to support self-management. Three investigators used standard content analysis methods to code the focus group transcripts. Emergent themes were reviewed with all collaborators, and final themes and representative quotes were validated with a sample of participants.

PARTICIPANTS: Fifty-three individuals with≥3 chronic conditions and experience using technology for health-related purposes.

KEY RESULTS: Focus group participants had an average of five chronic conditions. Participants reported using technology most frequently to search for health information (96 %), communicate with health care providers (92 %), track medical information (83 %), track medications (77 %), and support decision-making about treatment (55 %). Three themes emerged to guide eHealth technology development: (1) Patients with MCCs manage a high volume of information, visits, and self-care tasks; (2) they need to coordinate, synthesize, and reconcile health information from multiple providers and about different conditions; (3) their unique position at the hub of multiple health issues requires self-advocacy and expertise. Focus groups identified desirable eHealth resources and tools that reflect these themes.

CONCLUSIONS: Although patients with multiple health issues use eHealth technology to support self-care for specific conditions, they also desire tools that transcend disease boundaries. By addressing the holistic needs of patients with MCCs, eHealth technology can advance health care from a disease-centered to a patient-centered model.

KEY WORDS: eHealth; mobile health; chronic illness; multimorbidity; self-management.
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INTRODUCTION

The presence of multiple chronic conditions (MCCs) is associated with poor clinical outcomes, including more rapid functional decline[1] and increased rates of rehospitalization and mortality.[2,3] These outcomes are in part a function of substantial self-management and coordination challenges that arise when patients have multiple health issues. For example, patients with MCCs frequently face unwieldy medication regimens and daily self-care routines that may reduce adherence to recommended treatment plans.[4–8] They also often need to track and coordinate health information from different health care providers[9] and monitor and distinguish between symptoms from different diseases.[10–12] As a result, there is a great need for effective tools to support the self-care activities associated with multiple health issues.

One source of potential disease self-management and health care navigation support is eHealth technology.[13,14] eHealth technology comprises a range of patient-facing tools—information technology that engages patients in their health care—such as personal health records, web-based disease-management programs, telehealth devices (applications that deliver health-related services and information via telecommunications technologies), secure messaging applications, and health-related mobile applications.[15] Patients with chronic conditions are increasingly using eHealth technology to support their self-management,[16,17] and some now turn to online resources as a primary source of information.[18,19] These tools augment patients' self-care activities (a fundamental goal of health informatics technology)[20] by improving organization, providing information, and enhancing communication. Moreover, patients who use these resources report increased health-related knowledge and a greater sense of empowerment to improve their health.[21]

Despite the growing availability of eHealth technology, it is unclear whether existing tools are meeting the needs of patients with high levels of illness burden. The US Department of Health and Human Services has recommended enhancement of health information technology, including eHealth tools, to improve care for patients with MCCs.[22] To inform these efforts, we conducted a qualitative study of patients with MCCs who use technology for health-related purposes. Our objectives were to (1) understand self-management and health care navigation challenges that patients face because of their multiple health problems and (2) identify opportunities to enhance existing technology, or develop new applications and tools, to better support these patients.

METHODS

Study Recruitment

Study design was guided by established qualitative data collection and analysis principles.[23,24] We recruited individuals who receive care at an academic medical center or at a Veterans Affairs (VA) facility in Northern California, although many participants reported receiving care in other settings as well (Table 1). We approached 1,800 patients in clinic by mail and by e-mail (response rate 37 %). Interested participants were asked to complete a screening survey (Appendix 1) with information about their chronic conditions and sociodemographics as well as their experience and literacy[25] using technology for health-related purposes (e.g., personal health records, web-based programs, mobile applications).

Among the 550 individuals who completed the screening survey, 330 met the eligibility criteria for the focus groups (≥3 chronic conditions and experience using technology to help them care for their health or manage their health care, Appendix 1, Questions 1 and 6a–6c). Using purposive sampling, we constructed 10 groups of 3–8 patients who had one or more common conditions (e.g., diabetes, chronic pain, hypertension) and received care at the same institution (4 groups from the academic medical center, 6 groups from the VA). In certain instances, we constructed groups that were same sex and/or narrow in age range, especially if the individuals had a common condition that might generate sensitive discussion topics (e.g., post-traumatic stress disorder). These sampling methods resulted in invitations to 151 individuals (46 % of the eligible sample) to attend a focus group, 53 (35 %) of whom participated.

Table 1 Characteristics of Focus Group Participants (*N*=53)

	Mean (SD)	n (%)
Age	59 (11)	
Female		14 (26)
Race (*N*=52)*		
White, non-Hispanic		43 (81)
Black, non-Hispanic		3 (6)
Hispanic		5 (9)
Other, non-Hispanic		7 (13)
Employment (*N*=52)*		
Full or part time		17 (33)
Retired		25 (48)
Disabled or unemployed		23 (44)
Education (*N*=52)		
High school degree or less		4 (8)
Some college		23 (44)
College degree or more		25 (48)
Annual household income (*N*=51)		
<$50,000		22 (43)
$50,001–$75,000		8 (16)
>$75,001		21 (41)
Location of primary care*		
Academic medical center		18 (34)
Veterans Affairs health care system		27 (51)
Kaiser		5 (9)
Other community provider		5 (9)
Total number of conditions	5 (2)	
3		9 (17)
4		15 (28)
5		9 (17)
6		11 (21)
≥7		9 (17)
Chronic conditions*†		
High blood pressure		40 (75)
Chronic pain		34 (64)
Arthritis/rheumatism		26 (49)
Depression		21 (40)
Diabetes		18 (34)
Headaches/migraines		17 (32)
Post-traumatic stress disorder		16 (31)
Lung/breathing problem		12 (23)
1Cancer		9 (17)
Prostate problems		8 (15)

**Individuals could indicate more than one response item*

†Conditions reflect the ten most common conditions reported by patients. A full list of conditions is available in Appendix 4

Focus Group Procedures and Framework

After obtaining written informed consent from each focus group participant, a trained facilitator moderated discussions using a guide with pre-specified questions and discussion topics (Appendix 2). Sessions were audio-recorded, and two project team members observed the sessions and took detailed notes. Each focus group participant received a $50 gift card.

The focus group guide was developed using the Fit between Individual, Task, and Technology (FITT) framework.[26] This framework describes how technology adoption depends on the fit among attributes of the users, attributes of the technology, and attributes of tasks that users need to complete. We used this framework to query participants (individuals) about the challenges (tasks) that arise as a result of having to manage MCCs and to discuss patient-facing applications and tools (technology) that they currently use or that could be developed to support them in meeting these challenges. Although discussions were guided by the FITT framework, the facilitator also asked open-ended questions to allow novel themes to emerge (Appendix 2).

Qualitative Data Analysis

Focus group sessions were transcribed and analyzed using standard content analysis methods for coding textual data.[23] First, three research team members (DZ, EJ, DC) generated a preliminary set of codes based on the FITT framework and core questions in the focus group guide. Codes included challenges associated with having MCCs, tasks involved in self-care (e.g., medication management, coordinating multiple providers, maintaining health records), and technology that can be used to support these tasks (e.g., personal health records, mobile applications, video conferencing). After coding one focus group and reviewing and refining the codes with a qualitative research advisor (EL), two reviewers (EJ, DC) independently read and coded the transcripts from all focus groups, adding codes as needed for novel topics and discussing discrepancies with a third reviewer (DZ). Preliminary themes and representative quotes were identified by all three reviewers (DZ, EJ, DC) and discussed and refined with all members of the research team. ATLAS.ti qualitative data analysis software was used to support data analysis and synthesis (ATLAS.ti7, Scientific Software Development, Berlin, Germany). Findings were validated through a follow-up survey with a sample of focus group participants to ensure that the results reflected study subjects' perceptions and experiences. At the end of each focus group, all members were invited to participate in study validation by reviewing findings from the research team's analyses and completing an online survey. Of the 31 individuals who expressed interest, 22 (71 %) completed the validation survey (Appendix 3). Responses were reviewed by the research team to determine whether the themes resonated with study participants. The study was approved by the Stanford University Institutional Review Board.

RESULTS

Participant Characteristics

Participants in the ten focus groups (n=53) had a mean (SD) age of 59 (11), 74 % were male, and 43 % had an annual household income<$50,000. Participants reported receiving primary care within a range of health care systems, including the VA system (51 %), academic-affiliated clinics (34 %), and Kaiser (a large health maintenance organization) or community clinics (19 %) (Table 1).

The mean (SD) number of chronic conditions among participants was five (2), with the most common conditions including hypertension (75 %), chronic pain (64 %), arthritis (49 %), depression (40 %), diabetes (34 %), post-traumatic stress disorder (31 %), lung disease (23 %), cancer (17 %), and heart failure (13 %) (Table 1). Most participants reported using technology for health-related purposes daily to several times per week (51 %) or several times per month (40 %). The most common reasons for using technology included searching for health information (96 %), communicating with a health care provider (92 %), tracking medical information (83 %), tracking medications (77 %), and supporting decision-making about treatment (79 %) (Table 2).

Focus Group Themes

Analysis of focus group transcripts yielded three primary themes encompassing many of the challenges that patients face when managing MCCs: (1) Managing a high volume of information, self-management tasks, and communication; (2) coordinating, synthesizing, and reconciling information from different providers and about different conditions; (3) needing to serve as their own expert and advocate because of their unique combination of health issues. Across themes, many patients expressed emotional distress (e.g., stress, frustration) with their current ability to self-manage and coordinate care. Participants identified a number of opportunities to advance eHealth technology to better meet their needs (Table 3, Appendix 5).

Managing a High Volume of Information and Tasks. The first theme that emerged was that patients with MCCs have to manage a high volume of personal health information. One patient described this challenge as a multiplicative one, with the "paperwork" increasing with each health care encounter: "*You are trying to manage your health and, believe me, every time you see the doctor and you've got different conditions the paperwork just starts mounting.*" Many patients described self-management routines that include multiple medications taken throughout the day as well as complicated diets, exercise

Table 2 eHealth Technology Experience Among Focus Group Participants (*N*=53)

	Mean (SD)	n (%)
Frequency of health-related technology use		
Daily		8 (15)
1–5 times per week		19 (36)
1–3 times per month		21 (40)
Less than once per month		4 (8)
eHealth activities		
Searched for health information		51 (96)
Communicated with provider		49 (92)
Tracked medication list		41 (77)
Tracked medical information		44 (83)
Bought medications or supplies		29 (55)
Made treatment decisions		41 (79)
Visited online support group		13 (25)
Used health-related mobile application		18 (35)
Participated in health competition/game		2 (4)
Other		7 (14)
eHEALS score*	4.0 (1.0)	

**eHealth literacy measure in which respondents indicate their agreement with statements on a scale from 0 to 5, where 0=no experience, 1=strongly disagree and 5=strongly agree (e.g., I know how to find helpful health resources on the Internet) (Norman, Journal of Medical Internet Research, 2006)*

Table 3 Opportunities to Advance Technology to Support Patients with Multiple Chronic Conditions (MCCs)

Task	Challenges generated by MCCs*	Vol	Coord	Exp	Technology opportunities identified by patients with MCCs
Maintaining medical records	• High volume of records	x			• Portable medical record
	• Records from multiple health care systems	x	x		• Uniform platform for personal health records
	• Absence of a single comprehensive record system in case of emergency		x	x	
Obtaining health information	• Information sources are often disease specific and fragmented		x		• Online resources that consolidate information about MCCs
	• Shortage of information about condition interactions		x		• Bundled apps for MCCs; preloaded smart phones
Medication management	• Risk of med-med and med-condition interactions, especially when multiple prescribing providers/systems	x	x		• User-friendly resources to help patients identify potential med-med and med-condition interactions
	• Long and complicated medication regimens	x	x		• Organizational apps and web-based programs to assist with complicated medication regimens
	• Patient may be the only person who is aware of all medications at any given time			x	
Managing daily health-related activities	• Many self-management tasks are required throughout the day	x			• Centralized reminder system that integrates information from different health care systems
	• Patients frequently must schedule and remember a high volume of clinic, laboratory, and procedure appointments across multiple health care systems	x	x		• Apps and web-based programs that communicate self-management practices to provider • User-friendly automated reminder systems about daily self-management activities
Communicating with providers	• High volume of appointments	x			• Virtual clinic visits via e-mail or secure video conferencing
	• Certain conditions (pain, functional limitations) can make it challenging to seek care for other conditions		x		
	• Complexity of MCCs can make it difficult to seek emergency care from new provider		x	x	
Coordinating multiple providers	• Patients feel that they are responsible for coordinating their providers, but there are few opportunities to talk to them simultaneously		x	x	• Virtual clinic visits via e-mail or secure video-conferencing • Secure synchronous and asynchronous communication tools that interact with multiple providers across different health care systems
	• Different providers sometimes give conflicting advice/recommendations		x		
Peer support/social networking	• It is challenging for patients with MCCs to find peers with similar combinations of conditions			x	• Online support groups that connect patients with similar conditions • Avatar-enabled programs to facilitate sharing and support among individuals with privacy concerns
Caregiver support	• Caregivers may be overwhelmed by the number and complexity of health conditions		x		• Videoconferencing to enable participation of remote caregivers in clinic visits • Tools that inform caregivers about changes in health status, medications, and self-management routines

**Challenges generated by MCCs are categorized based on three themes that emerged during focus groups: Patients with MCCs need to (1) manage a high volume of information, visits, and self-care tasks (Vol), (2) coordinate, synthesize, and reconcile health information from multiple providers and about different conditions (Coord), and (3) serve as their own experts and advocates about health issues (Exp). An expanded version of this table with illustrative quotes from focus group participants is included in Appendix 5*

requirements, and other self-care tasks. A patient described the routine that she incorporated into her daily life to attempt to address overwhelming self-management needs: "*It's a struggle. It is! It's a huge struggle. Every week I have to put my meds in pill boxes because if I don't do that, with as many different medicines as I'm taking…To be perfectly honest I couldn't even tell you how many pill bottles it really is.*"

Technology use for volume management was common, for example, to organize medication regimens ("*I've worked out a spreadsheet and…put the medicine down and the time I have to take it and what dosage and all of that*") and to reduce clinic visits ("*I can save myself easily 15 or 20 visits a year just by messaging my [providers] and just communicating or by them calling me*"). Patients expressed interest in tools that could provide information about their multiple conditions, such as websites where "*you could learn about all these different conditions and have it consolidated in one place*" and mobile devices "*preloaded with apps that help with certain conditions.*" Patients also desired task management applications that crossed health care systems: "*It would be great if I could just get a monthly reminder that I could print out what was happening this month at all my different [clinics].*"

Coordinating Providers and Synthesizing Information. A second theme that emerged was the need for patients to coordinate their care for their multiple conditions, which involves communicating with providers across different settings, synthesizing information about different conditions and medications, and resolving conflicting recommendations. The central coordinating role that a patient with MCCs must assume was expressed by one patient who recognized that he alone was in a position to coordinate all of his health needs: "*I* *think coordinating with doctors is a big issue. I have so many [doctors] to start with, and for so many different things. I feel like I'm the one who has to coordinate and has to be aware of what's happening.*" This challenge was especially pronounced for complicated illnesses that require multiple providers: "*My problem is my illness crosses so many specialty boundaries…I am always playing tag between one of these four doctors trying to figure out if this is a [Multiple Sclerosis] episode I am having or is it actually an injury problem I am having due to spinal cord damage.*" Medication interactions were also a common problem for many patients. A patient expressed frustration that he had to proactively address potential harms that could emerge from medications prescribed by multiple physicians: "*Most doctors in my opinion don't know the side effects of drugs or their interactions. I personally have had some major episodes taking multiple medications. Now I research the medications before I take them together.*"

Many patients had experience using technology to detect potential medication interactions: "*I went home and went on the computer and I went searching all the medications and then looked at the other stuff I had been taking for other issues, you know is there any potential interaction.*" Although patients frequently used a personal health record that was provided by their primary health care system, the value of this tool decreased when patients received care in multiple settings: "*I wish there was something to coordinate things. Like, for instance, between two hospitals—if there was some way that we could coordinate information from multiple sources.*" Patients expressed great interest in technology that would facilitate communication with multiple providers. As one patient described it, even brief communication among all the health care professionals providing her care would greatly benefit the treatment plan for her multiple conditions: "*…so specialists and your primary care doctor all can sit down and talk about it for 10 minutes, then do the treatment plan right there. That in itself, the telecommunication, would save time, money, effort, miscommunication, a missed appointment, confusion, frustration… So I learn and the specialists all learn, and it's a win/win situation for everybody.*"

Serving as Expert and Advocate. The third challenge that emerged was that patients with MCCs often feel that they must serve as their own expert and advocate for their needs. This challenge frequently arose when patients had rare diseases or a combination of health problems that made them feel that they alone were fully aware of their constellation of symptoms and self-management needs. One patient said, "*For me having the mix of diseases, I have been walking around in a bubble thinking I'm the only one in the world that has got this.*" A second participant described how this challenge could also reverse the conventional knowledge balance of patients and physicians: "*You have to be your own advocate and research everything you can because sometimes you will be more cutting-edge than your doctor because you research it every day because it's something you live with.*"

Many patients described using technology in these situations to research their health conditions and actively participate in health care decisions. As one participant described it, this research was something done independently of interacting with medical professionals to build knowledge before clinical encounters: "*If you've got multiple problems, multiple-research it all and bring it with you; don't have them go fishing. You go fishing first then bring it in to them.*" Patients also expressed that technology empowered them in their role as advocate. "*I have…tried to arm myself with enough information with the technology, with the right care providers so that I control the disease; the disease doesn't control me.*" Participants identified a number of ways in which technology could facilitate their role as expert and advocate, for example, by helping them access new research findings, providing a forum to connect with other patients who have similar conditions, enabling health record storage, tracking, and sharing, and offering opportunities to consult remote specialists and to coordinate care with local providers.

Opportunities to Advance Technology to Support Patients with MCCs

Focus group participants discussed a number of technologies that they would like to see developed (or adapted) to better support their management of MCCs (Table 3 and Appendix 5). Some examples of technology opportunities identified by patients include:

- **Medical records**. Patients described a need for a uniform medical record platform and/or record portability to facilitate management of a high volume of records and ease coordination of records across multiple health care systems.
- **Online information**. Patients desired resources that consolidate and synthesize information about MCCs, such as applications that help identify potential medication-medication or condition-medication interactions.
- **Mobile apps**. Patients expressed interest in resources that would provide high-quality mobile app "bundles" that address their specific conditions as well as apps that provide assistance with common self-management challenges (e.g., complicated medication regimens) and integrate information from different health care systems (e.g., appointment reminders).
- **Communications technology.** Many patients were interested in technology (including secure messaging and video-conferencing) that would facilitate communication and coordination with multiple providers across different health care systems.

- **Social support applications and tools**. Patients described a need for online resources that would connect them with patients who had similar MCC profiles and support their roles as experts and advocates. They also desired videoconferencing and other tools (e.g., mobile apps) that would facilitate caregiver participation and engagement in their care.

DISCUSSION

This qualitative study identified several opportunities to develop and enhance eHealth technology to support self-management and health care navigation for patients with MCCs. The themes that emerged suggest that technology should aim to help patients manage a high volume of information and self-management tasks, facilitate coordination and synthesis of information from different providers and about different conditions, and support patients in their role of self-advocate and expert.

A common challenge for patients with MCCs is the need to obtain and synthesize information about multiple different health issues. Many individuals rely on the Internet for this purpose, turning to resources such as educational websites from major health care systems,[27–29] medical specialty and government websites,[30–32] and patient blogs and social networks.[33,34] Unfortunately, few existing websites address multiple conditions in an integrated fashion. There are some notable exceptions, such as PatientsLikeMe, a forum for individuals with chronic conditions that recently expanded their service so that patients can search for others with a similar set of comorbid conditions.[35] Other sites, such as WebMD and Medscape,[50,51] allow patients to identify potential adverse consequences related to medication interactions. These resources may serve as models for websites that help patients gather, synthesize, and reconcile information about MCCs.

Another frequent challenge for patients with MCCs is the need to communicate with multiple providers across different health care settings. This requires that patients have the ability to securely receive and share their information. Many patients expressed an interest in secure e-mail communication with providers (to reduce their number of clinic visits) and synchronous communication with providers from different disciplines and health care systems. Addressing these patient preferences is likely to pose a particular challenge for technology developers because of technical and data-security obstacles related to information-sharing between different systems' electronic health records.[36] Fortunately, there are now applications available that can facilitate information transfer and sharing, such as programs that enable information downloads from multiple electronic health records.[37] Furthermore, prototypes are emerging for systems that facilitate secure communication among providers in different health care settings.[38] Increasing adoption of these applications among health care systems will address a pervasive challenge for patients with MCCs.

A number of other barriers may impede the implementation of eHealth technology that addresses the needs of patients with MCCs. Developing applications that synthesize information about multiple conditions and discuss potential interactions and conflicting recommendations is clearly a challenging task, one that is further complicated by a shortage of evidence about treatment in the setting of MCCs.[1,8,39–43] In addition, insurers, employers, and other payers may be hesitant to reimburse eHealth technology until the effectiveness (and cost-effectiveness) of these tools has been established.[44] While many patients currently purchase personal devices and technology, this will not cover the cost of developing and maintaining technology that integrates electronic health record data and facilitates information exchange among health care systems.

Barriers at the patient level may also be present. Among individuals who are older or in ill health, many refrain from using eHealth technology because of distrust, discomfort, or lack of knowledge.[36,45–47] Even among the technology users in this study, individuals reported a wide range of eHealth literacy levels and frequency of technology use. However, use of online resources is steadily increasing among older adults,[48,49] and once online, individuals who have MCCs or who are in poor health are more likely to use health-related resources.[17,50,51] Furthermore, among eHealth technology users, patients with more chronic conditions tend to derive greater knowledge and increased motivation to improve their health.[50,51] Future research should explore variation in technology needs and preferences among patients in these different cohorts (for example, older individuals may prefer established websites and resources endorsed by their health care providers, while younger individuals who are more active technology users may rely more on mobile apps and social media). Additional efforts will be critical to determine how best to integrate information about multiple conditions and help patients reconcile recommendations from different providers.

There are several limitations of this study that warrant discussion. First, the purpose of this qualitative research was to elicit patients' experiences using technology to manage MCCs and to identify opportunities to better support their needs. As such, we focused on individuals who actively use health-related technology and did not attempt to address barriers to eHealth access and use. Second, focus group participants were drawn from health care systems in Northern California, a particularly information technology-literate region, so the spectrum of technology experience and desires may not reflect those of individuals residing in other geographic regions. However, the perspectives of patients with greater technology experience may be valuable in guiding future improvements. Finally, we drew over half of the focus group participants from the Veterans Affairs system because doing so contributed to greater diversity in chronic conditions, education, and socioeconomic status. While this resulted in several male-dominated focus groups, half of the groups included female participants and one of these comprised women only. In addition, our study cohort was slightly younger than the general population of patients with three or more chronic conditions (i.e., 62 vs. 49 % under the age of 65, respectively),[52] although this could be due in part to differences in chronic disease and multimorbidity definitions.

CONCLUSION

This study provides an in-depth understanding of the challenges that patients face when managing multiple chronic conditions. Although patients with multiple health issues use eHealth technology to support self-care for specific conditions, they also desire tools that transcend disease boundaries and help them synthesize and reconcile conflicting information, manage their high volume of personal health information, and support self-advocacy for their health care. By addressing these more holistic needs, eHealth technology can facilitate the advance of health care from a disease-centered model to one that is truly patient-centered.

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Corresponding Author: *Donna M. Zulman, M.D., M.S.; Center for Innovation to Implementation (Ci2i), VA Palo Alto Health Care System, 795 Willow Road, 152 MPD, Menlo Park, CA 94025, USA (e-mail: dzulman@stanford.edu).*

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