

Title: Accessibility and beyond: designing consumer health IT for disabled individuals

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Abstract

Purpose: The objective of this study was to develop consumer health IT design guidance for individuals with physical, cognitive, and sensory disabilities.

Scope: Designers have limited guidance upon which to draw when creating consumer health IT for individuals with disabilities. Existing guidance does not encompass individuals with disabilities' unique requirements for consumer health IT content and functionality and only partially accounts for accessibility requirements of individuals with non-visual functional limitations. The intent of the proposed study is to develop a broader set of design guidance for individuals with disabilities in the context of one form (i.e., mobile health applications) and one functional domain (i.e., health information communication with social network members) within consumer health IT.

Methods: This study employed a sequential, multi-method approach to empirically assess and draw design guidance for consumer health IT from individuals with disabilities' health information communication work systems. Data were collected through interviews, task analyses, journals, and focus groups. Data analysis was informed by qualitative content analysis methods but modified to meet the purpose of guiding design rather than building theory.

Results: Findings demonstrate that experiences with disability impact user needs both in terms of the types of functionality needed for effective health management (i.e., usefulness) and in terms of the ways such functionality is implemented (i.e., usability). While some of the needs reported parallel those reported from studies with individuals with chronic conditions, others are unique to those identifying as living with a disability. Moreover, findings demonstrate that existing consumer health IT must be redesigned or augmented to better allow for individuals with disabilities to fully engage with their health through such technological solutions. A secondary analysis further provided recommendations on how informatics designers and professionals can best partner with individuals with disabilities.

Key Words: individuals with disabilities, health information, communication, consumer health IT, mHealth, engineering design.

Purpose

The broad, long-term goal of this work is to improve health care quality through the development of consumer health IT that is responsive to the needs and preferences of diverse patient subpopulations. The objective of this self-contained health IT research study was to develop consumer health IT design guidance for one patient subpopulation, individuals with physical, cognitive, and sensory disabilities, who not only face challenges with health management, but also with technology use.

This objective was accomplished through three specific aims:

Specific Aim 1: By assessing individuals with disabilities' existing health information communication practices with social network members from a systems perspective.

Specific Aim 2: By identifying the challenges individuals with disabilities face in leveraging existing mobile consumer health IT solutions for health information communication with social network members from a systems perspective.

Specific Aim 3: By cooperatively generating (i.e., in partnership with individuals with disabilities) descriptive and prescriptive design guidance for consumer health IT based on an explication of existing practices and challenges.

Scope

Background: As the locus of health care shifts to home- and community-based settings, patients are increasingly viewed not as passive care recipients but as individuals who must be actively engaged in decisions and actions related to their health. (1, 2) A potential unintended consequence of the movement toward greater patient engagement is the increased marginalization of populations who face barriers to more active participation in their health and health care. (3) Successful patient engagement necessitates resources that align with the needs and preferences of diverse individuals. Consumer health IT developers, however, have predominantly focused on the needs of a limited number of demographic groups such as white/Caucasian race and 18-65 age group. (4) Only partial attention has been given to groups such as those with physical, cognitive, and sensory disability facing challenges related to health management and technology use. (5-7) Outside institutional settings, efforts to design health IT for individuals with disabilities have targeted interaction with healthcare providers (8-10) and monitoring. (11-14) Designers have seldom focused on individuals with disabilities' needs and preferences for consumer health IT that does not have these foci and that is commercially available despite evidence that other forms entering the marketplace, such as PHRs, do not currently meet the requirements of individuals with disabilities. (15)

Context: This study focused on complementing and building upon existing design guidance from the International Standards Organization, World Wide Web Consortium, and General Services

Administration IT Accessibility Workforce targeting individuals with disabilities. In particular, we sought to explicate the ways in which individuals with disabilities currently engage in processes of self-management and the challenges they face when engaging with existing consumer health IT solutions as a basis for generating novel design guidance. The study focused on one form (i.e., mobile health) and one functional domain (i.e., health information communication with social network members) within consumer health IT. Mobile health (mHealth) was selected as a focus because of its growing relevance to health management and because accessibility guidelines for such technologies remain in early stages. (16-19) The functional domain of health information communication with social network members was selected because previous research has suggested meaningful differences in how individuals with and without disabilities approach this aspect of health information management and because relevant consumer health technologies remain limited in number and functionality. (20-24)

Although this study focused on social networks, we did not conduct a social network analysis, nor did we focus on popular social media platforms such as Facebook, Twitter, or Instagram. Social network analysis is primarily concerned with the structure of a social network, including its size, density, and cohesion. In contrast, this study focused on one task of health information management: health information communication with social network members. Therefore, the focus was not on the structure of the network, but rather on the needs and preferences of individuals with disabilities for consumer health IT that supports engagement with their social network members to accomplish self-management goals. Similarly, although individuals may engage with people in their social network through popular social media sites, this study took a more expansive view of social networks to include anyone with whom an individual had an affect-based relationship (whether or not they interacted with this individual through social media).

The study consisted of three phases. Phase one consisted of an interview-based exploration of individuals with disabilities' existing health information communication work systems. Phase two consisted of a task analysis and journal-based exploration of challenges with the use of existing consumer health IT solutions that arose from misalignment with work system components. Phase three consisted of focus groups and iterative conversations aimed at generating additional design guidance.

Settings:

Recruitment took place through our partner sites which included two rehabilitation hospitals, two centers for independent living, multiple clinics at the University of Virginia Medical Center, and multiple nonprofit organizations. For phases one and two, participants were given the option of engaging in research-related activities at home, at one of the partner sites, or at a public library (in a private room). All focus groups took place at the University of Virginia, at one of the partner sites, or at a public library. When participants were unable to attend a focus group session, they were given the option of answering these questions through an interview.

Participants:

Individuals were considered eligible for screening if they were 18 years of age or older and self-reported as living with a disability. A phone-based screening interview was conducted with each individual during which two functional assessment tools typically used in rehabilitative services were used to begin characterizing an individual's disability (i.e., Functional Independence Measure [FIM™] and the Quick Disabilities of the Arm, Shoulder, and Hand [QuickDASH]). (25-27) Additionally, individuals were asked to provide self-reported information about their diagnoses and functional abilities along with demographic information. If this assessment suggested that an individual was living with a cognitive disability, an in-person meeting was scheduled during which the Montreal Cognitive Assessment (MoCA) (www.mocatest.org) was administered. Individuals were considered eligible if they scored 18 or higher on this assessment. Apart from this eligibility criteria, maximum variance sampling (28) was used to recruit individuals across disability experiences and demographic characteristics.

Fifty-five individuals participated in the study. All fifty-five participated in phase one, 50 participated in the task analysis portion of phase 2, 32 participated in the journaling portion of phase 3 and in phase 4. Of the 55 participants, 34 were female and 21 were male. Of the 55 participants, 34 identified as white, 13 as Black or African American, 7 as more than one race, and 1 chose not to disclose their racial identity. Forty-six participants identified as having a physical disability, 23 as having a sensory disability, 14 as having a cognitive disability, and 12 as having a psychiatric disability. In total, participants reported 86 distinct health conditions and disabilities.

Incidence and Prevalence: Given that this study encompassed a wide range of diagnoses, it is difficult to report an incidence rate (it is difficult to find reliable incidence rate reporting for disability more generally). Varying statistics are reported for the prevalence of disability in the United States. Reports attributable to the U.S. Census Bureau, CDC, and Cornell University for example between 2010 and 2016 report prevalence between 12.8% and 22%. (29-31) These statistics are lower when children are included and higher when young children or all children are excluded.

Methods

Study Design: This study will employ a sequential, multi-method approach to empirically assess and draw design guidance for consumer health IT from individuals with disabilities' health information communication work systems. The study consisted of three data collection phases: 1) interview-based exploration of existing work systems, 2) task analysis and journal-based exploration of challenges to using existing consumer health IT, and 3) focus group-based exploration of potential design solutions. All data were self-reported and collected retrospectively. Analysis of qualitative data was informed by qualitative content analysis methods (32-35) but modified to meet the purpose of guiding design rather than building theory.

Data Sources/Collection: Participants were recruited from multiple community sites to take part in all phases of the study. Participants served as partners throughout the study and continue to be involved in developing study products.

Phase One Data Collection: Maximum variance sampling was based first on type of disability and the 5 racial and 2 ethnic groups of primary interest to AHRQ. It was subsequently based upon other demographic characteristics, such as gender, socioeconomic status, and geographic location. Data were collected through in-person interviews. Interviewees were first asked to create a visual representation of their social network and then asked a series of questions about each included individual. (36) Interviewees were then asked about if and how they communicate health information to each of the included social network members and how aspects of their health information communication work system shape these practices. (37)

Phase Two Data Collection: Phase two consisted of the task analysis (38-40) and journaling activities. All individuals who participated in phase one activities were invited to participate in phase two activities. In task analysis activities, participants were asked to interact with three mHealth applications designed to support health information communication with social network members. Participants were given the option of interacting with the apps on either a smartphone or tablet (all on iOS platform). The ordering of apps tested was counterbalanced across participants. All task analyses were video-recorded and observed by the moderator who used posttest inquiries to determine root causes of any observed task failures or difficulties.

Upon completion of the task analysis, participants were invited to attend an orientation session for the journaling activity. During the orientation, participants were provided refresher tutorials on all of the apps but assigned one primary app to use for the two-week-long data collection period. Participants were asked to try to use the app in their everyday lives during this period and provide feedback to the research team daily. Feedback was obtained through an online survey, series of text messages, or a phone call based upon the participant's preference.

Phase Three Data Collection: Although we originally proposed the use of design sessions, interactions with our study population over a two-year period suggested that the use of focus groups (and interviews when focus group participation was difficult for an individual) may be more appropriate. Focus groups were thus used to obtain summative feedback on phase two activities, to discuss future design directions, and to discuss ways in which studies of this nature could be modified in the future to better meet the realities of our participants' daily lives.

Interventions: This was not an interventional study.

Measures: Qualitative instruments were designed for the main components of the study. These instruments were grounded in previous qualitative work in addition to frameworks from macroergonomics. Additionally, the task analysis protocol was informed by best practices for this type of evaluation. The instruments used in this study are available upon request.

Limitations: This study was subject to two primary limitations. First, some of the data collection approaches were subject to recall bias, including interviews and focus groups. To ensure triangulation from data collection activities that are not as prone to recall bias, task analysis and daily journaling were used. Second, qualitative analysis and interpretation were susceptible to the assumptions and biases of the researchers. To mitigate this effect, multiple researchers were engaged in qualitative analysis and met regularly to ensure consistency in coding.

Results

Principal Findings:

Phase one: Phase one findings focused on dimensions of health information communication similar to those we have reported in previous studies; that is, we explored to whom, what, how, and why individuals with disabilities communicate about their health to others. Of particular interest in our phase one data was the question of how disability shaped rationales for communicating about health. In other words, we were interested in understanding when and how disability became an explicit part of the decision-making for the dimensions of health information communication noted above. This analysis demonstrated four overarching rationales related to disability: 1. Support (statements related to getting and giving assistance), 2. Disclosure (statements related to negotiating boundaries of information-sharing with others), 3. Advocacy (statements related to promoting the understanding of disability and disability rights), and 4. Logistics (statements related to the impact of disability on the mechanics of communication).

Phase two: Phase two focused on participants' experiences engaging with the three mHealth apps both in a lab (task analysis) and naturalistic (journaling in the home and community) environment. Findings demonstrated that participants found challenges to the usability of the applications that spanned changes that could be made to all four dimensions of health IT, including content (e.g., apps did not include American Sign Language as a language option), functionality (e.g., voiceover and dictation implemented incorrectly), interface (e.g., difficulty seeing and selecting buttons located at the corners or border of the screen), and technology platform (e.g., tapping and selecting buttons on small screens).

Phase three: Phase three analysis sought to complement our interpretation of phase one and phase two data by asking participants to share additional thoughts related to use of the mHealth apps and about health information communication in general, particularly as related to the design of revised or new technologies. These findings fell into four primary categories: 1. Additional general functionality (e.g., ability to enter detailed dietary information and receive recommendations about exercise); 2. Extension of existing functionality (e.g., ability to correlate data entered into app, ability to sync information entered with provider's EHR); 3. Additional accessibility features (e.g., ability to use Siri to plot graphs verbally); 4. Improved usability (e.g., better distinguishing features between types of pages within app; ability to customize units of measurement).

In addition to these findings, we have worked with our participants to better understand how health IT researchers can best partner with individuals with disabilities for future research efforts. These findings demonstrate actions that should be taken by researchers before and during field work activities. These findings are relevant both to the overarching research process and to the use of mHealth technology when working with individuals with disabilities. Examples of actions relevant to the overarching research process include not making assumptions about framing disability as something negative or as a barrier (in other words, adopting a social as opposed to medical model of disability) and being upfront and honest about one's experience working with individuals with disabilities, asking participants to help the research team learn about preferred terminology (this is particularly important when the research team is working with a broad population and is unable to ensure that all disabilities and their related terminology is included in the training). Example of actions relevant to the use of mHealth include creating videos with all possible accessibility features such as captioning and touch buttons and making screen protectors specific to individuals who are blind available for use if desired.

Outcomes: Beyond the results reported above, this study has resulted in interview, task analysis, journaling, and focus group protocols that may be used or modified by others researching the health information communication practices of individuals with disabilities or chronic conditions. Additionally, our journaling protocol was modified from our original proposal to be interactive (through voice or text-based interactions in Google Voice) to better meet the needs of our study population. This protocol may be of interest to others working with hard to reach populations.

Discussion: The intent of the proposed study was to gain insight about how best to design consumer health IT to meet the needs of individuals with disabilities. In particular, this study focused on one form and one functional domain of consumer health IT, mHealth and health information communication with social network members. This study builds upon our previous knowledge in multiple ways, both in terms of how to make consumer health IT more usable and useful for individuals with disabilities and how to more effectively partner with individuals with disabilities in the context of informatics research. Several findings from this study suggest that the needs of individuals with disabilities for consumer health IT overlap with the needs of other populations. For example, many populations have discussed the need for tools that facilitate interaction with social network members to obtain and receive instrumental, informational, and education support. (37, 41-43) Additionally, however, this study points to needs that may be more specific to individuals with disabilities. For example, findings from phase one suggest that individuals with disabilities may communicate health information to social network members as a means of engaging in broader advocacy to improve their overall quality of life. This type of functionality does not exist within mHealth applications designed to support health information communication with social network members but could make such technology more useful for individuals with disabilities. Similarly, design decisions made for reasons of aesthetic (such as placing buttons in corners of the screen) may preclude some individuals with disabilities from using the technology effectively, and many may abandon the technology if they cannot see the peripheries of a screen or have tremors that make it difficult to access

these locations on a screen. Finally, informatics research is often conducted with a population defined by a shared diagnosis, and the research team will likely be trained with in-depth knowledge about living with this particular health condition. However, there is also value in looking at the whole person and understanding how multiple disabilities or the intersection of disability and chronic illness manifest in terms of needs for consumer health IT. Findings from this study will help researchers entering this intersectional space better prepare to meet the needs of their participants with disabilities.

Conclusions, Significance, and Implications: This study explored how individuals with disabilities engage in communicating health information with their social network members and with mHealth technologies designed to support this task. Through this exploration, we gained insight into how consumer health IT may be better designed in terms of usability and usefulness to meet the needs of this marginalized population. It is important to note that although some findings demonstrated the synergy between the needs of this population and the needs of other populations, many unique needs were demonstrated for individuals with disabilities. Beyond the important task of incorporating these findings into future design efforts, our study more broadly demonstrates the essential work of partnering with individuals with disabilities when designing new or redesigning existing consumer health IT. To this end, we further gained and look forward to sharing our insights into how informatics researchers should plan to work with individuals with disabilities to further accelerate the incorporation of their needs into consumer health IT design.

List of Publications and Products

1. Wellbeloved-Stone CA, Weppner JL, Valdez, RS. A systematic review of telerehabilitation and mHealth interventions for spinal cord injury. *Current Physical Medicine and Rehabilitation Reports* 2016; 4(4), 295-311.
2. Valdez RS, Lemke M, Smith G, et al. *Accessibility and beyond: designing consumer health IT for disabled individuals*. H3IT; Chicago, IL; 2016.
3. Valdez RS. Patient work as design foundation: the case of health information communication. Division of Health Sciences Informatics, Informatics Grand Rounds, at Johns Hopkins University; Baltimore, MD; 2016.
4. Valdez RS, Wellbeloved-Stone CA, Lemke M, et al. *Accessibility and beyond: designing consumer health IT for disabled individuals*. I-PrACTICE; Madison, WI; 2017.
5. Ozkaynak M, Valdez RS, Demiris G, et al. Innovation in workflow methods for consumer health informatics. American Medical Informatics Association Annual Symposium; Washington, D.C.; 2017.
6. Valdez RS. Patient work as design foundation: the case of health information communication. Center for the Science of Health Care Delivery Grand Rounds, Mayo Clinics; Rochester, MN; 2017.
7. Valdez RS. Considering consumer health in ergonomics standards development. International Standards Organization TC159/SC3 Technical Advisory Group Meeting; Yellow Springs, Ohio; 2017.

8. Valdez RS. Including disability in conversations about health care disparity. Department of Physical Medicine and Rehabilitation Grand Rounds, University of Virginia; Charlottesville, VA; 2017.
9. Jaswal V, Ellcessor E, Valdez R, et al. Disability and design: A roundtable discussion. Disability Studies Symposium, University of Virginia; Charlottesville, VA; 2018.
10. Benda N, Thomas A, Valdez R, et al. Human factors approaches to improving health equity: where have we been and where should we go next? Human Factors and Ergonomics Society 2018 International Symposium on Human Factors and Ergonomics in Health Care; Boston, MA; 2018.
11. Valdez RS. Patient work as design foundation: the case of health information communication. IBM Health Informatics Distinguished Speakers Series, IBM Thomas J Watson Research Center; Yorktown Heights, NY; 2018.

In Preparation

We have a series of manuscripts under preparation that disseminate findings from all three phases and share our guidance for informatics researchers interested in working with individuals with disabilities. The first of these manuscripts is intended for JMIR and presents our main findings from phase one. The second of these manuscripts is intended for JAMIA and advocates for the inclusion of individuals with disabilities in informatics research and presents our guidance for doing so effectively. The third manuscript is intended for Applied Ergonomics and presents our main findings from phases two and three.

References

1. Dentzer S. Rx for the 'blockbuster drug' of patient engagement. *Health Aff (Millwood)*. 2013 Feb;32(2):202. PubMed PMID: 23381509.
2. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)*. 2013 Feb;32(2):223-31. PubMed PMID: 23381514.
3. Thomson R, Murtagh M, Khaw FM. Tensions in public health policy: patient engagement, evidence-based public health and health inequalities. *Qual Saf Health Care*. 2005 Dec;14(6):398-400. PubMed PMID: 16326781. Pubmed Central PMCID: 1744099.
4. Gibbons MC, Wilson RF, Samal L, Lehmann CU, Dickersin K, Lehmann HP, et al. Impact of consumer health informatics applications. *Evid Rep Technol Assess (Full Rep)*. Rockville, MD. 2009 Oct;(188):1-546. PubMed PMID: 20629477.
5. Gell NM, Rosenberg DE, Demiris G, Lacroix AZ, Patel KV. Patterns of technology use among older adults with and without disabilities. *Gerontologist*. 2013 Dec 30. PubMed PMID: 24379019.
6. Archer N, Keshavjee K, Demers C, Lee R. Online self-management interventions for chronically ill patients: cognitive impairment and technology issues. *Int J Med Inform*. 2014 Apr;83(4):264-72. PubMed PMID: 24507762.
7. Goldberg L, Lide B, Lowry S, Massett HA, O'Connell T, Preece J, et al. Usability and accessibility in consumer health informatics current trends and future challenges. *Am J Prev Med*. 2011 May;40(5 Suppl 2):S187-97. PubMed PMID: 21521594.
8. Johansson T, Wild C. Telemedicine in acute stroke management: systematic review. *Int J Technol Assess Health Care*. 2010 Apr;26(2):149-55. PubMed PMID: 20392317.
9. Kairy D, Lehoux P, Vincent C, Visintin M. A systematic review of clinical outcomes, clinical process, healthcare utilization and costs associated with telerehabilitation. *Disabil Rehabil*. 2009;31(6):427-47. PubMed PMID: 18720118.
10. Forducey PG, Glueckauf RL, Bergquist TF, Maheu MM, Yutsis M. Telehealth for persons with severe functional disabilities and their caregivers: facilitating self-care management in the home setting. *Psychol Serv*. 2012 May;9(2):144-62. PubMed PMID: 22662729. Pubmed Central PMCID: 3375593.
11. Demiris G, Hensel BK. Technologies for an aging society: a systematic review of "smart home" applications. *Yearb Med Inform*. 2008;47 (Suppl 1):33-40. PubMed PMID: 18660873.
12. Carrillo MC, Dishman E, Plowman T. Everyday technologies for Alzheimer's disease care: Research findings, directions, and challenges. *Alzheimers Dement*. 2009 Nov;5(6):479-88. PubMed PMID: 19896587.
13. Chaudhuri S, Thompson H, Demiris G. Fall detection devices and their use with older adults: a systematic review. *J Geriatr Phys Ther*. 2013 Jan 8;1-19. PubMed PMID: 24406708.
14. Reeder B, Meyer E, Lazar A, Chaudhuri S, Thompson HJ, Demiris G. Framing the evidence for health smart homes and home-based consumer health technologies as a public health intervention for independent aging: a systematic review. *Int J Med Inform*. 2013 Jul;82(7):565-79. PubMed PMID: 23639263. Pubmed Central PMCID: 3740158.

15. Karavite D. The accessibility of electronic personal health records for people with disabilities. International Symposium on Human Factors and Ergonomics in Health Care; Baltimore, MD: 2013..
16. Deloitte Center for Health Solutions. mHealth in an mWorld: How mobile technology is transforming health care. 2012.
17. World Health Organization. mHealth: New horizons for health through mobile technologies. Geneva, Switzerland: 2011.
18. PricewaterhouseCoopers. Emerging mHealth: Paths for Growth. 2012.
19. Harper S, Thiessen P, Yesilada Y. Research Report on Mobile Web Accessibility. 2013.
20. Lippold T, Burns J. Social support and intellectual disabilities: a comparison between social networks of adults with intellectual disability and those with physical disability. *J Intellect Disabil Res : JIDR*. 2009 May;53(5):463-73. PubMed PMID: 19302469.
21. Jones R, Carpenter J, Schrijner P, Cambridge P, Tate A, Beecham J, et al. The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *J Appl Res Intellect Disabil*. 2006;19:285-95. Epub June 6, 2005.
22. Bolwijn P, Santen-Hoeufft M, Baars H, Kaplan C, van der Linden S. The social network characteristics of fibromyalgia patients compared with healthy controls. *Arthritis Care Res*. 1996 Feb; 9(1):18-26. PubMed PMID: 8945109.
23. Braithwaite DO, Eckstein NJ. How people with disabilities communicatively manage assistance: helping as instrumental social support. *J Appl Commun Res*. 2003;31(1):1-26.
24. Valdez RS. Creating a foundation for the design of culturally informed consumer health IT [Dissertation]: University of Wisconsin-Madison; 2012.
25. Rehab Measures: Functional Independence Measure 2013 [cited 2014 June 2]. Available from: <http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=889>.
26. University of Buffalo. About the FIM system; 2014 [cited 2014 June 2]. Available from: http://www.udsmr.org/WebModules/FIM/Fim_About.aspx.
27. Institute for Work & Health. The DASH outcome measure: disabilities of the arm, shoulder and hand: 2014 [cited 2014 June 2]. Available from: <http://dash.iwh.on.ca/quickdash>.
28. Patton MQ. Qualitative research and evaluation methods. Thousand Oaks, CA: Sage Publications.; 2001.
29. Centers for Disease Control and Prevention. Key findings: prevalence of disability and disability type among adults, United States - 2013. Atlanta, Georgia: CDC, 2013.
30. Cornell University. 2016 Disability status report United States. Ithaca, New York: Cornell University, 2016.
31. Taylor D. Disability statistics from the U.S. Census Bureau in 2017/2018. *Disability Compendium*: 2018 February 13.
32. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures, and measures to achieve trustworthiness. *Nurse Educ Today*. 2004 Feb;24(2):105-12. PubMed PMID: 14769454.
33. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005 Nov;15(9):1277-88. PubMed PMID: 16204405.
34. Saldaña J. The coding manual for qualitative researchers. London, England: SAGE Publications Limited; 2009.

35. Sandelowski M. What's in a name? qualitative description revisited. *Res Nurs Health*. 2010 Feb;33(1):77-84. PubMed PMID: 20014004.
36. Antonucci TC, Akiyama H. Social networks in adult life and preliminary examination of the convoy model. *J Gerontol*. 1987 Sep;42(5):519-27. PubMed PMID: 3624811.
37. Valdez RS, Brennan PF. Exploring patients' health information communication practices with social network members as a foundation for consumer health IT design. *Int J Med Inform*. 2015;84(5):363-74. PubMed PMID: 25704761.
38. Weinger M, Wiklund M, Gardner-Bonneau D. *Handbook of human factors in medical device design*. Boca Raton, FL: CRC Press; 2011.
39. Wiklund M, Kendler J, Strohlic A. *Usability testing of medical devices*. Boca Raton, FL: CRC Press; 2010.
40. Kaye R, North R, Peterson M. *UPCARE: an analysis, description, and education tool for medical device use problems*. FDA Center for Devices and Radiological Health; 2003.
41. Valdez RS, Guterbock TM, Fitzgibbon K, Williams IC, Wellbeloved-Stone CA, Bears JE, Menefee HK. From loquacious to reticent: understanding patient health information communication to guide consumer health IT design. *J Am Med Inform*. 2017; 24 (4):680-96. PubMed PMID: 28069667.
42. Skeels MM, Unruh KT, Powell C, Pratt W. Catalyzing social support for breast cancer patients. *CHI Conf Proc*. 2010:173-82. PubMed PMID: 21654894. PubMed Central PMCID: PMC3108040..
43. Weiss JB, Lorenzi NM, editors. *Online communication and support for cancer patients: a relationship-centric design framework*. *AMIA Annu Symp Proc*. 2005:799-803. PubMed PMID: 16779150. PubMed Central PMCID: PMC1560480.