Exploring patients’ health information communication practices with social network members as a foundation for consumer health IT design

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\textbf{A B S T R A C T}

Background: There is a need to ensure that the growing number of consumer health information technologies designed to support patient engagement account for the larger social context in which health is managed. Basic research on how patients engage this larger social context is needed as a precursor to the development of patient-centered consumer health information technology (IT) solutions.

Purpose: The purpose of this study was to inform the broader design of consumer health IT by characterizing patients’ existing health information communication practices with their social network members.

Methods: This qualitative study took place between 2010 and 2012 in a Midwestern city. Eighteen patients with chronic conditions participated in a semi-structured interview that was analyzed using qualitative content analysis and descriptive statistics. Emphasis was placed on recruiting a sample representing diverse cultural groups and including participants of low socioeconomic status.

Results: Participants’ social networks included a wide range of individuals, spanning biological relatives, divinities, and second-degree relationships. Participants’ rationales for health information communication reflected seven themes: (1) characteristics and circumstances of the person, (2) characteristics and circumstances of the relationship, (3) structure and composition of the social network, (4) content of the message, (5) orientation of the goal, (6) dimensions of the context, and (7) adaptive practices.

Conclusions: This study demonstrates that patients’ health information communication practices are multidimensional, engaging individuals beyond formal and informal caregivers and driven by characteristics of their personal lives and larger social contexts in addition to their health problem. New models of consumer health IT must be created to better align with the realities of patients’ communication routines.

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1. Introduction

A contemporary and critical aspect of health care delivery is patient engagement [1]. Engagement in this context has been defined as “actions individuals must take to obtain the greatest benefit from health care services available to them” [2]. Discourse surrounding patient engagement often focuses on an individual’s solitary actions or actions requiring interaction with the formal health care delivery system. However, patient engagement is not confined to these activities, but rather extends to actions taking place within the larger context of a social network [3–7]. As consumer health information technologies intended to support patient engagement proliferate, there is a need to ensure that these technologies integrate functionality supporting the ways in which patients leverage social network members in their health management practices. Consequently, in this study, we take a functional approach to consumer health information technology (IT) design, recognizing that this functionality may be implemented across multiple technology platforms. This paper provides a starting point for design of consumer health IT supporting health information communication with patients’ social network members by characterizing the composition of these networks and patients’ rationales for interacting with them.

Involving social network members in health management requires communicating (i.e., sharing or relating content through various media with multiple individuals) health issues and concerns to them, which is an essential yet burdensome task for patients [3]. However, existing consumer health IT developed to support health information communication has largely focused on four communication pathways: (1) between clinicians and patients, (2) between clinicians and caregivers, (3) among caregivers, and (4) among patients [8–15]. Only a limited number of consumer health information technologies (e.g., Epic’s MyChart, Microsoft HealthVault, Tyze and CaringBridge) include functionality to support the task of health information communication with social network members. For example, Epic’s MyChart allows patients to share their entire health care institution-generated personal health record with individuals who act as proxies for or primary informal caregivers to the patient. Microsoft HealthVault (www.healthvault.com) facilitates creating and sharing a personal health record that is independent of any particular health care institution; however, this often requires patients to take responsibility for populating their record. Unlike Epic’s MyChart, Microsoft HealthVault allows patients to provide access to specific elements of their record to a wider range of social network members. Whereas Epic’s MyChart and Microsoft Health Vault predominantly support communication of the health record, CaringBridge (caringbridge.org) and Tyze (tyze.com) enable individuals with health concerns to create status updates and to request instrumental and emotional support from family and friends with web access.

The fragmented nature of these solutions suggests that development of consumer health IT supporting health information communication with social network members is in its early stages. Consequently, an opportunity lies not only in the integration [16] of existing functionality but also in the assessment of patients’ needs for such technology. Multiple models of the design process include a provision for needs assessment [17–19]. Furthermore, within the medical informatics community, it is widely recognized that the development of new technologies requires meaningful involvement of intended users to ensure alignment with daily routines [20–26]. Technologies not aligned with realities of patients’ lives may increase physical and psychological burdens and decrease patients’ ability to appropriately use the technology, raising the potential for unintended consequences [27–32]. Informaticians have sought to understand users’ needs at multiple points in the design process including before and after advancing a specific design solution [33–36]. Increasingly, the value of assessing user needs early in the design process has been recognized. For example, the Agency for Healthcare Research and Quality has called for basic research on end users’ personal health information management practices as a precursor to development of consumer health IT solutions [37]. Therefore, the purpose of this study was to characterize two aspects (i.e., to whom and why health information is communicated) of patients’ health information communication practices with their social network members (i.e., the design space) to provide a foundation for the broader design of consumer health IT supporting this task.

To date, only a limited number of studies have explicitly sought to understand patients’ needs for consumer health IT that facilitates health information communication with social network members [5–7]. The strength of these studies lies in the development of design guidance for consumer health IT based on in-depth explorations of the health information communication practices of patients with chronic conditions. The present study builds directly upon these efforts in three ways. First, compared to previous studies focusing on specific aspects of participants’ rationales for health information communication, such as patients’ goals [7] or interpersonal relationships with informal caregivers [6], this study explicitly takes an expansive approach to assessing the range of rationales participants articulate regarding their communication practices. Such an approach is critical given that these same studies have alluded to the influence of a range of factors including interpersonal relationships with a wide range of individuals, message content, goals, and environmental factors on patients’ health information communication practices. Second, whereas previous studies have asked about social networks as a whole, this study required participants to explicitly reflect on interactions with each self-identified social network member. The intent of this method was to simultaneously gain a more systematic and holistic understanding of patients’ health information communication practices. Finally, previous studies have not reported on socioeconomic or cultural demographics of the study population. This study, however, gives particular attention to recruiting a sample representative of diverse cultural groups and inclusive of participants of low socioeconomic status. Emphasis on these demographic characteristics will ensure that future consumer health IT is responsive to the daily lives of those adversely affected by health care disparities [38,39].
2. Materials and methods

2.1. Sampling

This qualitative study, conducted in a mid-size Midwestern city between 2010 and 2012 is a part of a larger effort to understand patients’ health information communication practices as a foundation for consumer health IT design. The University of Wisconsin-Madison Health Sciences Institutional Review Board approved this study, and all participants provided informed consent. Recruitment occurred at two federally qualified health centers. These sites were chosen because they serve culturally diverse patient populations and because they predominantly serve patients who are of low socioeconomic status. Eligible patients were over the age of 18, had a diagnosis consistent with Type 2 diabetes, and spoke English. Diabetes was the focus of this study because when searching for design solutions, it is important to select domains that enable understanding of salient features of the problem. Diabetes was an appropriate domain because as a chronic disease growing in prevalence, it may be considered a prototypical health problem. Moreover, because it is a condition requiring intense personal engagement, diabetes patients are likely to have rich health information communication practices that may be studied. Finally, as a health problem disproportionally affecting racial and ethnic minorities and individuals of low socioeconomic status [40,41], a focus on diabetes facilitated recruitment of these populations.

Recruiters (i.e., nurse practitioners, dieticians, diabetes educators) screened patients for eligibility using the clinics’ electronic health record. Eligible patients received a scripted invitation. If they expressed interest, eligible patients were provided with a recruitment packet that included a study information sheet and a short demographic survey. The short demographic survey contained twenty-five questions related to age, gender, race, ethnicity, nationality, other cultural affiliations, education, socioeconomic status, health status, and technology use. All patients who completed the demographic survey received a token of appreciation. Although there was no intent to tie responses to cultural identities, maximum variance sampling [42] based first on self-identified cultural identity (race, ethnicity, nationality, and other cultural affiliations) and then on other demographic characteristics was used. Thirty-one individuals completed the survey. Of these, eighteen were recruited, one declined, six were contacted multiple times without responding, five were not contacted, and one was unreachable using the contact information provided.

2.2. Data collection and analysis

In this study segment, the first author conducted a semi-structured interview with each participant in his/her home or at the clinic. The home was broadly defined to include any location in which participants spent the majority of their time (e.g., one participant requested conducting the interview in the bakery he owned). Participants were first guided through a structured process to create a visual representation of their social network [43]. A list of potential network members (e.g., son, stepmother, neighbors) was provided to assist participants with this process. After the visual representation was complete, participants were asked to provide information regarding each social network member’s demographic characteristics and relationship with the participant.

Participants were then presented with four types of health information: (1) time and place of doctor’s appointments, (2) information about diabetes self-care and self-management, (3) daily observations about health, and (4) test results from clinic visits. These four types of health information were chosen because they span (1) emotionally sensitive and non-sensitive health information, (2) information generated by both the provider and patient, and (3) logistic, personal, and reference information [44]. As a result, it is likely that these forms of health information are communicated in different ways, resulting in a more comprehensive understanding of with whom and why participants communicate health information. In this study, communication was conceptualized as both an act and non-act. Thus, for each social network member, participants were asked whether or not they communicate each of the four types of health information. They were then asked about rationales for communicating or not communicating each type of health information to each social network member. This data collection methodology was piloted and refined prior to conducting this study [45].

All participants provided informed consent and received $20 upon completing the interview. Interview time averaged one hour and seven minutes. Relevant information obtained during other study-related interviews was also analyzed. Interviews were audio-recorded and professionally transcribed. All transcripts were reviewed by the primary author prior to analysis.

Data were analyzed using descriptive statistics (IBM SPSS Statistics® 19) and qualitative content analysis (QSR NVIVO® 9 & 10) [46–50]. Qualitative content analysis was grounded in Hsieh and Shannon’s [50] specific procedure for conventional content analysis, which involved gaining an overall impression of the data and engaging in an iterative process of inductively drawing themes. The advantage of deriving categories of interest from the data is that this approach is firmly grounded in patients’ lived experiences. Such an approach may be considered “patient-centered” from a health sciences perspective [51] and “user-centered” from an information technology design perspective [52]. Simultaneous coding was used when units of text contained multiple meanings [48]. The primary author and a second coder independently analyzed 20% of the data. Discrepancies were resolved through discussion and consensus building [48,53]. Decisions made during these meetings were synthesized into a preliminary codebook, which guided the remainder of the primary author’s analysis. Throughout the coding process, findings were discussed with experts in consumer health informatics, engineering design, nursing, and medical anthropology. A final codebook was created to formally define and provide examples for the contents of each theme and category [48].

2.3. Establishing rigor

Four criteria were used to establish rigor in this interpretative study: credibility, transferability, dependability, and
confirmability [49,54–57]. In addition to establishing credibility through multiple data analysts, credibility was enhanced by engaging 20% of the sample in a journaling activity to capture communication practices (methodological triangulation) [58]. Furthermore, the first author engaged in critical discussions about the research process with colleagues throughout data collection and analysis (peer debriefing) and provided participants with an opportunity to review the data collected (member checking). Transferability was established through written study protocols and a demographic survey that provided a multidimensional characterization of the participants. Finally, the authors ensured dependability and confirmability through documentation of the rationales behind all methodological decisions, reflexive journaling, and an audit trail of all study materials.

3. Results

3.1. Sample characteristics

Eighteen participants were recruited into the study (Table 1). Participants’ genders were evenly distributed and their average age was 49 years. Participants reported a wide range of self-identified cultural identities including “African American,” “Diverse,” “Hispanic,” “Middle Eastern,” and “White.” The majority of participants reported less than $30,000 per year in household income. Participants had been diagnosed with diabetes for periods ranging from 10 months to 32 years and had an average self-rated health status of 2 (fair) on a 5-point scale (where 1 = poor, 5 = excellent). While some participants never used the Internet, others used it daily. Of the fourteen participants who reported on their locations of Internet access, nine indicated access at home, five indicated access at a library, and two indicated access each at a friend or family member’s home, at work, and at a community center.

Participants’ social networks included individuals and groups of individuals (e.g., uncles, friends). The size of participants’ social networks ranged from seven to seventeen members, defined by the participant as either a group or an individual. In total, participants’ social networks contained members, both male and female, ranging in age from the first through ninth decade, as well as deceased. Frequency of contact ranged from daily to more than every three months, with some participants reporting no contact with some social network members. The geographic proximity of social network members varied from residing in the same household to living abroad. Participants communicated to social network members in multiple languages including English, Spanish, Arabic, and “tongues.” Qualitative content analysis yielded twelve categories of relationships present in participants’ social networks (Table 2). Group social network members sometimes contained individuals who spanned multiple genders, ages, and other traits. Participants reported both communicating and not communicating health information with the majority of social network member types. For example, while some participants reported communicating health information to their biological relatives, others reported not communicating to these types of individuals.

3.2. Participants’ rationales for health information communication with their social network members

Participants’ rationales for health information communication reflected seven broad themes. The first six themes represent the types of rationales participants provided for communicating or not communicating health information: (1) characteristics and circumstances of the person, (2) characteristics and circumstances of the relationship, (3) structure and composition of the social network, (4) content of the message, (5) orientation of the goal, and (6) dimensions of the context. Theme 7, adaptive practices, represents statements participants made about the evolving and compensatory nature of health information communication. The numbers in this paragraph correspond to the numbers in Fig. 1.

3.2.1. Theme 1: Characteristics and circumstances of the person

Participants’ rationales for health information communication invoked their own and their social network members’ characteristics and circumstances. The rationales indicated that participants were responsive to both their own and their social network members’ mental state. Participants mentioned the importance of social network members’ general level of awareness: “I communicate with him and tell him nothing because he don’t understand... ‘cause he got a dementia problem” in addition to their awareness pertaining specifically to health and diabetes: “Because she knows more about the test results than anybody else does.” The thought patterns of both individuals, including their beliefs: “Leave it
alone, God gonna took care of it” and priorities: “I just want to focus on getting rid of this weight, getting my body fixed so I can go back to work. So I’m just really kind of focused on that” were also accounted for when making communication decisions. Others noted that their mood and the mood of their social network members had a bearing on whether or not health information was communicated: “If I’m in my upbeat mode, being more sociable. Not putting a concrete wall between me and the other person.”

The determination of whether or not to communicate health information was furthermore based on health status and professional, educational, and personal experiences. Participants accounted for the presence and severity of diagnoses, signs, and symptoms. While some communicated to certain social network members only when they felt that their health had improved, others stated that there was no reason to communicate health information when their diabetes was well managed: “They’re all – all of my numbers are pretty much in line, so there’s no big extreme going on with anything. My cholesterol’s down and – yeah, we wouldn’t want to talk about that. It’s all fine.” Moreover, many participants indicated that they would communicate health information to social network members if an emergency were to arise: “Or if I’m around him at the time and the medical may present itself at that time.” The rationales provided by participants also reflected involvement in life events and activities external to the individual. For example, participants acknowledged communicating to social network members because of their medical training and current or previous practice as a formal or informal caregiver: “Because she works in the nursing field… yeah. She was trained as a nurse assistant’s or something, or medical something, and she was a phlebotomist for a while.” Other experiences invoked included previous interactions with social network members as well as individual

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<th>Table 2 – Categories of roles in the social network.</th>
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Fig. 1 – Rationales for health information communication with social network members.
practices: “Like I say, I’m a recovering drug addict because I don’t—I think I recovered a long time ago but I can’t put myself in position to be around people like that.”

Participants further accounted for their own and others’ membership in demographic groups, availability, and technological resources. In terms of demographic groups, age was primarily invoked as a reason not to communicate with children and less often as a reason not to communicate with elderly: “They too little to understand anything.” Gender was predominantly mentioned as a rationale for communicating with women and for not communicating with men: “Again, men want you to get to the point. They don’t want to hear all about what color the walls were in the doctor’s office and how the doctor made you feel. They don’t want to hear that. Get to the point. So I try to remember that when I’m with men.” Participants also reflected on their own and their social network members’ overall levels of busyness and specific schedule of engagements and obligations: “Cause we worked on the plane crew, so we had about an hour a day where we sat at the time at the airport.” Finally, rationales for communication were reactive to the technological resources, such as telephones and computers, which participants and their social network members could access for communication purposes: “He don’t have his own phone or nothing like that.”

3.2.2. Theme 2: Characteristics and circumstances of the relationship

Participants’ rationales for health information communication also accounted for characteristics and circumstances of the relationship between themselves and their social network members. The presence or absence of communication was impacted by the longevity, frequency, and timing of the participants’ interactions with social network members as well as their relative geographic locations. Participants considered the length of time that they had known social network members: “I been knowing her for years” and how often they connected: “Because we see each other more often.” Additionally, whether or not the participant-social network member dyad had made successful contact since the participant had health information to communicate was also reported: “I haven’t. Yeah, I haven’t. I haven’t been able to reach them. I mean, I’ve had messages, but I haven’t been able to.” The effects of geographic proximity: “We’ve lived together for 20 years, of course we’re gonna be like that” and remoteness: “Cause sometimes I feel she should know, being she is out of town, she’ll know what’s going on with me up here” were also invoked as grounds for communication. Participants considered a wide range of geographic distances as remote, for example: “She lives way out in [town an hour away]” to “Cause they don’t live here either…” They’re in [another country].”

Rationales for communicating further reflected the presence of emotions between the dyad and the established scope of the relationship. The degree to which a participant felt close to a social network member was often mentioned: “I mean anybody I’m real close to like that, I do it”; “The rest of them I’m not that close to, so I wouldn’t really tell ’em any information.” Participants further described the impact of positive, negative, and conflicting emotions on the decision of whether or not to communicate health information: “He would care and we would talk about stuff like that. He’s really one of my closest friends. He just really got me agitated right now.” In addition to the emotional space between the dyad, participants mentioned following established patterns within the relationship. These patterns included conversational priorities: “We’re just family and there’s so much other crap we got to talk about” and involvement and degree of openness in one another’s lives: “We don’t really keep secrets from each other.”

Moreover, participants accounted for social and biological ties that defined the dyad. In providing this rationale, participants often directly invoked the role played by social network members in their life. Many of the roles described in Table 2 were specified including biological relatives, legal relatives, friends, neighborhoods, health care providers, and second-degree relationships. Participants mentioned the importance of specific ties including that between spouses: “Yeah, she’s my wife and she’s supposed to know everything that’s going on with me” and that between mother and child, “You kinda go to your mom ‘cause she’s been taking care of you for years… She has always been the one that you would come to…. “The role of individuals who are friends but act as family members was also mentioned: “...we kinda adopt people in our family, especially if you don’t have family, where you live, and we will just adopt you. You’re there for Christmas and all the holidays and whenever you want. So she is family, so she knows a lot of things that’s going on in ours.”

3.2.3. Theme 3: Structure and composition of the social network

The presence of other individuals and technologies in addition to the dyad also impacted participants’ health information communication practices. Participants’ rationales for communicating health information to social network members accounted for the presence and absence of other individuals to whom they could communicate. Thus, participants noted not communicating to a social network member because of the existence of another appropriate information recipient: “[The bus company] has me down as locations that are where I usually go, the clinics and stuff, so I don’t really need to talk to [my case manager] about [the time and place of my doctors’ appointments].” At times, participants communicated with divinities instead of other social network members: “But oh well, I just pray about it, so I don’t talk about it.” Conversely, other participants spoke to a social network member because they lacked an alternative: “Yes, and sometimes I just let her know so somebody else knows what I’m doing because I live alone. I have nobody to tell.”

The existence of a mutual relationship or a health information technology through which social network members could receive the message also influenced communication. Mutual relationships promoted communication when a participant wanted to assume the role of informant: “Plus, if I don’t tell them, the girls will, because that’s the way my sisters are.” Mutual relationships inhibited communication when a participant believed that the information had already reached the social network member: “That’s, again, like if my mom hasn’t told her. Usually my mom beats me, tells her first.” Electronic health records also inhibited communication with social network members who were health care providers because they served as communication platforms between clinicians: “She knows those. She gets them on the computer when I come in.
She has those from my file in the computer because the tests and everything that Doctor [name] does, they’re shared right now.”

Additionally, participants accounted for the circumstances of individuals outside of the dyad. In particular, participants considered the health status of others within their social network and other individuals known to social network members:

“We’ve had some conversations because her husband was diagnosed with diabetes, and she was a little bit – well, he’s another skinny little shit...Well, mainly we would just kick around what might have pushed him, gotten the high blood sugar and what he was eating because normally he likes the Mediterranean style diet and stuff like that and just bounced around a few theories, mainly that.

3.2.4. Theme 4: Content of the message
When describing their health information communication rationales, participants invoked the presence and substance of the information. The presence of health information was influenced by participants’ own observations in addition to their interactions with health care providers: “Well, I haven’t noticed anything so I can’t tell him what I haven’t observed.” Participants assessed the substance of the health information in terms of its specificity, weight, and personal nature and invoked these characteristics as rationales for not communicating health information. Some noted that while they were willing to communicate general test results, they were less willing to communicate health information that was more directly related to bodily functions: “Cuz I felt like I was talking about my body parts. It was spilling over in my yarn, and that was irritating”. Similarly, another participant stated that while he communicated appointments to his daughter, he didn’t communicate graver health information such as existing complications and the potential long-term consequences of diabetes that may distress her. “Well, the appointments I’m sure I would tell her about, but most of the other stuff is heavy.” Participants further reflected on whether or not the health information was important or compelling enough to warrant communication: “I wouldn’t share probably anything as mundane as like when my visits were or what the results of the tests that I didn’t deem important but everything else, yes.”

3.2.5. Theme 5: Orientation of the goal
Participants’ health information communication rationales reflected the objectives they sought to achieve. These rationales were oriented, in part, to organizing activities with social network members. Thus, participants communicated health information such as the time and place of doctors’ appointments to facilitate schedule coordination and the details of activities such as meals and childcare: “Yeah, because sometimes I’ll be – [my son] will be needing to bring [my grandson] over and I might have an appointment that I’m coming back from, or just location-type things, where I’ll be and when.”

Participants also sought to manage communication objectives related to managing a conversation and information flow over time. At times, participants refrained from communicating health information because there were other topics to discuss: “We’ve usually got other things to talk about.” However, when other conversation topics were exhausted, health information was seen as a default topic: “Cause we hang out and eventually run out of cool things to talk about.” Participants noted following-up on previous communication, promoting continuity: “She would ask me something like, ‘How was your shoulder doing’ and I would say, ‘I’m seeing the doctor’ and then... I would either call her or email her what the doctor had to say.”

Furthermore, participants strove to be responsive to social network members’ inquiries and interests yet also sought to establish quid pro quo with social network members both now and in the future. When asked a specific question by a social network member, participants provided the requested information: “She talks to me on a daily basis and she will ask, I will tell.” Additionally, participants conveyed health information they believed would be of interest to social network members: “They want to know. They want to know almost every day.” Conversely, health information that was not directly sought or not believed to be of interest to social network members was left uncommunicated: “He never asks me how is my diabetes going or nothing like that. If he don’t ask, then I don’t provide.” Moreover, participants noted working toward establishing reciprocity in communication practices with social network members: “[My kids] should know, so I can know about theirs. I feel if I share mine with them, they’ll share theirs with me.”

Participants managed their own and social network members’ level of awareness regarding their health status and strove to preserve their public image. Participants noted communicating health information that promoted self-reflection: “I think it helps me, and partly it helps me remember if we talk about it... [It helps me remember] where I’m at with it. Yeah, kind of how I’m doing.” Communication was also moderated based on whether or not participants wanted others to have general knowledge about their health status: “I just would let [my friend] know so he and his family know how I’m doing.” Participants mentioned withholding health information when they believed that its disclosure would make them appear vulnerable. One participant said the following in reference to his teenage child: “Don’t want her to see I’m mortal. After all, I’m the spider killer, the monster chaser.”

Participants’ need for assistance and their perception of others’ need for such assistance also impacted their communication practices. The types of assistance expressed spanned emotional: “It’s kind of encouraging each other” and logistical: “I mean shit I want her to know and she probably needs to know when I have appointments where she knows when she can make me give her a ride someplace or not.” Support was only sought or offered when deemed necessary or relevant: “If there is a serious test result about something or sometimes it could be a minor thing and I just think that I can handle the situation without involving their attentiveness to me.” Moreover, participants refrained from communicating health information when they believed social network members would be unable to provide the required assistance: “There’s not much they can do to help.”

Finally, participants’ health information communication was aimed toward decreasing both parties’ burden in terms of effort and consequences and increasing both parties’ enjoyment. When unduly taxing in terms of effort or consequences,
participants avoided health information communication with social network members. One participant withheld health information from her sister to avoid interference: “She was drivin’ me up the wall and over the wall and whew! She was going to – well she started out goin’ to the doctor appointments with me to actually find out what was goin’ on. After she found out what was goin’ on she was like okay sis you can’t eat that cookie, you can’t drink the juice, you eatin’ too much bread. Oh she was just!” In contrast, participants communicated health information when they believed it could alleviate burden: “[I communicate] ‘cause you know he might be worried or something.” Similarly, communication of health information was sometimes seen as a means to increasing happiness: “When she knows that I’ve been healthy for two, three months with no problems, she’s excited.”

3.2.6. Theme 6: Dimensions of the context
Participants’ rationales reflected features of the broader environment where health information communication occurs. They accounted for the attributes of the health condition, such as whether or not symptoms of the condition were visible to others. One participant noted that because diabetes does not have readily apparent symptoms, it is difficult to talk about: “Diabetes is such a smoky disease you know. It’s not as if I have really bad aches and pains, or sores, you know. It’s just kind of a sneaky thing you know.” Both the timing of events: “Oh, depends on when we talk. If I have a future appointment coming up, I’ll tell her that I do” and the circumstances of the moment, such as both parties’ mood and the flow of conversation: “Then, it would just suppose to be an incidental mentioning, I think. Just a byproduct of what was going on” impacted participants’ health information communication. Additionally, participants acknowledged following the norms of the cultural, familial, professional, and political groups of which they were members:

Arabs are very emotional. They are very caring for something like that. They feel that they are sick more than the sick themselves. That’s why you try most of the time to avoid going through the detail unless you are in a very, very bad condition. While, if you are okay and so on, you didn’t need to make them worry about that.

3.2.7. Theme 7: Adaptive practices
Participants’ rationales for health information communication suggested actively managing evolving circumstances and multiple priorities. Participants noted that their social network and rationales for health information communication with a specific social network member changed over time. For example, one participant described why she used to communicate to her sister: “Use to was when I was living in the house” why she no longer does: “Oh she was just! You’re supposed to eat this. You gotta eat that. She was just driving me up the wall” and why she may in the future: “Well, maybe if I start back talkin’ to her… Probably so. ‘Cause I know she’ll ask me.” Participants also spoke about balancing multiple rationales (e.g., the goal of promoting enjoyment, the affect-based tie of the relationship, and the well-being of the participant) when making a communication decision.

4. Discussion
The results of this study demonstrate that the design space for consumer health IT functionality supporting patient health information communication with their social network members is larger than typically conceptualized in terms of network composition and communication rationales. Patients communicate health information to a large variety of individuals, including but extending far beyond health care providers and immediate family members. Moreover, their rationales for communication are driven not only by their health problems but also by characteristics of their personal lives and the larger social environments in which they are embedded. Consequently, it is imperative that new models of consumer health IT supporting patient engagement are created not only to include patient portal access for care partners [59], but also to provide support for health information communication practices that draw on complex social networks and rationales.

This study both confirms and extends the design space for consumer health IT in terms of the breadth of individuals and rationales identified by previous design-related studies of patients’ health information communication with social network members [5–7]. It corroborates that patients communicate health information to relatives, partners, friends, neighbors, professional affiliates, health care providers, and faith-based community members. Moreover, it presents unique evidence that health information is communicated to household members, divinities, and second-degree relationships. It also supports previous conclusions that patients’ communication rationales reflect individuals’ physical and emotional states (theme 1), the established scope of individuals’ relationships with their social network members (theme 2), the quality of the health information (theme 4), and individuals’ goals of preserving an image while obtaining necessary assistance (theme 5). Furthermore, it highlights additional rationales, including the presence of other types of individuals and technologies in the social network structure (theme 3) and contextual features such as social norms of cultural groups (theme 6).

The explication of the design space generated in this study may be conceptualized as descriptive design guidance for consumer health IT. Descriptive guidance provides an explanation of salient user characteristics, such as interpersonal relationships, physical surroundings, and social and environmental factors [23]. It is not meant to be exhaustive or prescribe specific design actions, but rather, to be demonstrative. The purpose, therefore, of descriptive design guidance is to enable designers to anchor construction of health IT interventions in empirical evidence of users needs while simultaneously providing flexibility for the generation of creative solutions. Descriptive design guidance has been valued by the health IT community both in the form presented in this study (i.e., the explication of key themes across participants) [35,60] and in other forms such as personas [61,62] and scenarios [63,64]. All of these forms of descriptive design guidance are aggregate representations of the user population, serving as a foundation for the design process by illustrating features of the phenomenon (in this case patients’
health information communication with social network members) that should be considered when making design decisions.

It is important to emphasize that while descriptive design guidance serves this foundational role, it is only one input into the application of a thorough user-centered design process [23,26,65]. Thus, while the results of this study describe aspects of the design space for consumer health IT oriented to supporting health information communication with social network members, future studies and development efforts must prioritize the needs within this space for different consumer populations. Moreover, collaborative design and evaluation sessions with users will further elucidate how best to translate the needs articulated within this design space into design features. Early efforts to translate this guidance into design may, therefore, only be responsive to a portion of the articulated design space. However, the foundational knowledge generated through this study provides direction for iterative development efforts.

The original intent, therefore, was not to be prescriptive; however, specific design opportunities present in the results are important to articulate. First, underlying all seven themes is the implication that it is time to move beyond blanket access permissions and simple group classifications. There is a need to design informatics tools that support the more nuanced communication practices in which patients are engaged. This will require creating tools that not only facilitate control of with whom specific information elements are shared, as available in Microsoft HealthVault, but also the absolute (e.g., 3 pm every Monday) and relative (e.g., after each clinical appointment) timing of such sharing. Second, theme 3 demonstrates that patients’ health information communication is not only motivated by their own and their social network members’ circumstances but also by their social network members’ social networks (i.e., friends of friends). Consequently, instead of supporting communication between individual “hubs and spokes,” new models of consumer health IT should facilitate connections between networks of individuals. Third, the range of individuals to whom participants communicate health information emphasizes the necessity of developing functionality often overlooked by designers such as communication with divinities and religious community members. Although perhaps originally viewed as outside the purview of consumer health IT, innovative solutions are beginning to be created in this domain, including the “prayer request” forums on carepages.com and wwpray.org, that may be integrated into and enhanced within consumer health IT. Finally, some of our participants noted communicating with individuals in languages other than English. This practice underscores the need for consumer health IT systems to accurately translate health information between languages. Such a need may be particularly pronounced in refugee, immigrant, or temporary overseas worker populations that maintain close ties with multiple linguistic communities.

In addition to those directions, a key design implication results from the fact that health information communication occurs in the context of other daily communication routines. Patients’ health information communication practices are in part shaped by general decisions surrounding with whom, when, and why communication occurs. For instance, themes 1 and 2 illustrate that participants embed health information communication into larger communication routines shaped, respectively, by individuals’ busyness and emotional connections. Other assessments of patients’ health management practices (e.g., Moen and Brennan’s investigation of health information storage) [44] have also shown that individuals approach health similarly to other aspects of their lives. Consequently, new models of consumer health IT should allow for more seamless integration of health and non-health related tasks, better supporting the ways in which health management is enmeshed with larger daily routines [26]. Designers of consumer health IT can capitalize on the basic functions of mobile tools that enable this form of seamless integration.

This study’s strength lies in its systematic, in-depth exploration of patients’ health information communication practices with their social network members. However, there were aspects of our approach that may have led to an extensive but not exhaustive explication of the design space. Social desirability may have influenced participants’ responses, resulting in only partial revelation of to whom and why health information is communicated. To minimize this, each encounter was prefaced with reassurances that no correct answers existed and that the researchers were genuinely interested in the full range of participants’ experiences. Additionally, the design space elucidated may be limited in scope because the tool used to define participants’ social networks only contained three circles of affective ties. A likely consequence of this conceptualization is the absence of acquaintances from the social networks identified [66]. Given that our participants had minimal online presence, the specification of the design space may also be limited with regard to patients’ existing health information communication practices with their online social networks (i.e., through general social media platforms and online health communities [67,68]). Complementary needs assessment efforts are, therefore, currently underway to better specify the design space in terms of patients’ acquaintances and online relationships [69]. These ongoing efforts leverage mixed methods approaches, enabling further breadth of understanding of the design space through qualitative methods and an understanding of differences in communication practices across types of individuals and health information through quantitative methods. Finally, as specified by multiple representations of the engineering design process [17–19], application of the design guidance generated from these in-depth needs assessments is only a first step. Formative evaluation during the design process is required to reveal other aspects of patients’ health information communication practices that must be accommodated by a consumer health IT solution for any specific population.

5. Conclusion

This study demonstrates that new models of consumer health IT must be created to better support the ways in which patients engage in health information communication with social network members. It underscores that transformation is needed not only in terms of with whom health information may be
Summary points
What was already known on the topic:

- Health management activities occur within the larger context of a social network.
- Patients’ daily routines must be reflected in consumer health IT design.

What this study added to our knowledge:

- Patients’ health information communication practices are complex.
- New models of consumer health IT must better support existing connections.

shared but also in terms of how such information is processed and made available to social network members. The rich descriptive design guidance generated in this study may serve as a foundation for this development process. Future efforts which leverage patients as full partners in the design process [70,71] are required to translate this descriptive guidance into concrete consumer health IT solutions and to assess the resulting solutions on outcomes such as use, usability, usefulness, and, ultimately, health outcomes.

Conflict of interest statement
The authors declare that they have no financial or personal relationships with other people or organizations that could inappropriately influence (bias) this study.

Authors’ contributions
Both authors of this manuscript contributed to the conception and design of the study and acquisition of data or analysis and interpretation of data, (2) drafting of the article or revising it critically for important intellectual content, and (3) final approval of the version submitted.

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