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Comparing Information Needs of Health Care Providers and Older Adults: Findings from a Wellness Study

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Abstract

Consumer health informatics technologies have the potential to enhance shared decision-making and communication between older adults, health care providers, and other stakeholders. The objective of this study was to characterize the information needs of these stakeholders to inform the design of informatics tools that support wellness in older adults. We conducted four focus groups with 31 older adults and three focus groups with 10 health care providers to explore information needs, goals, and preferences for information sharing. Analysis of focus group transcripts was performed to identify and compare themes for different stakeholders. We identified four themes related to information activities: perceived goals of others, perceived information needs of others, information sharing by older adults, and role of family members. Older adults, family members and health care providers differ in their information needs. We provide recommendations to facilitate design and adoption of informatics tools that connect these stakeholders. Larger studies are needed to characterize different stakeholder goals, information needs and preferences.

Keywords

Informatics; Decision Making; Communication; Aging; Gerontology

Introduction

The ethical need for shared decision-making between older adult patients and health care providers (HCPs) [1] creates an attendant need for information sharing between these groups of stakeholders [2]. There is a need to track patient-reported information about psychosocial functioning and health behaviors to improve patient-centered care and population-based research [3]. Consumer health informatics technologies such as personal health records

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(PHRs) have the potential to enhance patient-provider communication and shared decision-making with older adults, but must be integrated into care processes and support systems [4]. Other stakeholders may share access to the health information of older adults because older adult patients often bring family members to help interpret information and make decisions during visits with health care providers [5,6].

Prior research has been conducted concerning the information needs of HCPs [7-9] and older adults [10-13]. However, many of these studies have focused on the information needs of HCPs and less attention has been paid to the similarities and differences of, or even potential discrepancies between, the information needs of HCPs, older adults and family members [9]. The needs, beliefs, and values of older adults and other stakeholders are important factors in the design of technology to support older adult independence and well-being at home [14]. Usability, usefulness, credibility, and goals have been identified as barriers to technology implementation and adoption [15]. Thus, informatics tools that are not designed to fit the needs of patients, family members, and HCPs may not be acceptable and may be abandoned.

An integrated informatics approach that supports all stakeholders must be informed by the perspectives of all participants to design integrated systems that standardize reporting outcomes and coordinate processes [16]. To avoid usability challenges and barriers to technology adoption, efforts to evaluate stakeholder information needs are the first step in the design and evaluation of new informatics tools [17]. Therefore, in this qualitative descriptive study, our objective was to describe and compare the goals, information needs, and preferences for information sharing for older adults and health care providers engaged in activities to support wellness in older adults.

Materials and Methods

Recruitment

Older adult participants were recruited to participate in focus group sessions through presentations at an independent retirement community in Seattle, WA. Health care providers in the Pacific Northwest region of the United States were recruited through gerontology mailing lists. All study protocols were approved by the University of Washington Internal Review Board.

Sample and Setting

There were two groups of participants: older adults and HCPs involved in the care of older adults. Inclusion criteria for older adults were willingness to participate, current residence in the participating community, and being at least 62 years of age. Inclusion criteria for HCPs were willingness to participate, currently working as a health care provider, and having experience specifically in the care of older adults. All participants provided informed consent prior to study enrollment.

Data Collection

We conducted four focus groups [18] with 31 older adults and three focus groups with 10 health care providers to explore information needs, preferences for information sharing, and group members' thoughts about the information needs of other stakeholders. Focus groups, or group interviews, are an efficient way to collect data from multiple stakeholders with similar characteristics [18]. Focus group questions are developed according to the purpose of each study [18] and data analysis may or may not be concerned with participant interactions during focus group sessions [19]. In the case of information design studies, questions can be concerned with individual information needs and preferences for the use of information and technology.

All focus group sessions were conducted by two researchers who acted as moderator and note taker (BR and TL). After an explanation of the purpose of the study and a conceptual model of holistic wellness composed of social, spiritual, physical, and cognitive categories [20,21], participants were asked questions about how they currently use, communicate, and share health information with other stakeholders. Participants were also asked about potential ways they would like to use information.

Focus group protocol questions were generated from literature review and prior research experience to solicit perceived information needs, preferences, and goals of stakeholders and interactions with other stakeholders. As prompts for discussion, participants were shown visualizations that demonstrated short-term and longitudinal health trends based on data from a previous wellness study in an independent retirement community [12,13]. Visual displays were organized by social, spiritual, physical, and cognitive categories to match the underlying conceptual framework of the original study [20]. A discussion of the development of the visual displays has been reported elsewhere [22].

The focus group protocol was pilot tested with clinicians and informaticians from the research group and revised twice before data collection. The main area of research for the group is technology and aging. Thus, the researchers involved in the protocol design and test were familiar with the needs of older adults as users of technology and information. Data collection for older adults took place in February 2012 at the independent retirement community and for HCPs in September and October 2011. All focus group sessions were recorded with a digital audio recorder and transcribed verbatim by members of the research team, yielding 217 pages of material for analysis.

Data Analysis

Thematic analysis [23] was conducted with the aim of characterizing perceived information needs and information uses by older adults, health care providers, and other stakeholders. All seven transcripts were double-coded by two researchers (BR and TL) for inter-rater reliability. Analysis began with independent coding of one HCP transcript by both researchers. A codebook was first developed through discussion until agreement was reached for each code. Next, the codebook was checked for content validity by two researchers (HT and GD) and then used to independently code all three HCP transcripts. The same codebook was applied to a randomly selected transcript of a session with older adults

and modified slightly to fit the different participant group. All four older adult session transcripts were independently coded by the same two researchers (BR and TL) using the modified codebook. For each of the seven transcripts, both researchers met to discuss and reconcile coding before moving onto the next transcript. Coded content was grouped thematically by one researcher (BR) and reviewed by a second researcher (TL). Themes were compared by stakeholder group to determine similarities and differences.

Results

Twenty-two females and nine males participated in the older adult focus groups. Nine females and one male participated in the HCP focus groups. Each focus group session lasted between 60 and 75 minutes. Four themes were identified and described: *perceived goals of others*, *perceived information needs of others*, *information sharing by older adults* and *role of family members*. The first three themes pertain mainly to the two primary stakeholder groups, older adults and health care providers, while the fourth pertains to family involvement.

Perceived Goals of Others

This theme is concerned with the level of awareness of the goals of the other group when considering the two primary stakeholder groups. Health care providers responded with greater frequency and detail about the perceived goals of older adults than older adult participants did about the goals of HCPs. Health care providers also discussed the need to tailor care based on individual patient goals and information. One overarching theme consistently reported by HCPs was that they perceived that older adult patients and families are often more concerned about social and spiritual wellness than physical and cognitive measures of wellness. The comments of a participant from HCP focus group 1 emphasized these differences: “No matter what your priorities are, as a health care provider, their priorities are always different... their biggest concern might be spiritual and nothing else matters.” The comments of a participant in HCP focus group 2 also supported this idea: “A lot of patients would say, ‘I don’t care about my cognitive well-being, what really matters to me is spiritual or social.’” In contrast, one participant from older adult focus group 2 inquired: “Does the health care provider usually take into his overview the social and spiritual well-being?” Another older adult participant asked: “Do you think if the patient took the information on social and spiritual wellness to your health care provider, would he consider that you were being kind of bumptious?”

Perceived Information Needs of Others

This theme pertains to the perception of the information needs of one group by the other in the patient-provider relationship. HCPs responded with a greater level of certainty about their perceptions of the information needs of older adults. The following quote from a HCP focus group participant illustrates this idea: “My hunch is that most patients have their own ideas about what you should track and if you could keep track of that, that would have a lot more meaning for them... if you’re going to put effort somewhere, it would be in finding ways of developing scales that you can agree on with patients and then keeping track of them over time, so that when they come back you can have a meaningful dialogue about

how their life is going.” In contrast to HCPs’ thoughts about older adult information needs and preferences, older adult participants expressed uncertainties about providing unsolicited information to their HCPs. In general, older adult participants expressed doubts about bringing novel information sources to a visit with their provider. When considering his doctor’s potential reaction to bringing new types of personal health information to a visit, one older adult participant exemplified these types of doubts by responding: “I don’t know if he would be interested.”

Information Sharing by Older Adults

This theme describes preferences for information sharing by older adults from the standpoint of HCPs and older adults. Both HCPs and older adults recognized that preferences for information sharing by older adults vary based on individual characteristics and attitudes. The following quote from a participant in HCP focus group 1 illustrates two possible outcomes based on individual patient factors:

I don’t know that all patients will be open to giving up all that data... people who are educated and proactive about their health would be more inclined to say: ‘Yeah, let me give you all this data so that you could tell me how I’m doing in all these areas and how I can improve my quality of life’ for instance, or: ‘You know what? I don’t really like doctors; I don’t really like medicine at all so I have no interest in giving you all of this. I just want you to give me medication because I have a cold.’

HCPs also noted the potential usefulness of information tools to communicate with older adults and their family members about care planning for older adults.

Older adults were open to sharing information with HCPs and family members. Friends were mentioned by a few participants as substitutes for family members in their social networks. The following quote from a participant in older adult focus group 4 illustrates sharing of information with family members: “In my family, anyways, I think I would compare and I would tend to brag about or find where I was... 80, 81% that’s very good. You brag about it (laughter). You’ve got graphs to show it.” This attitude toward sharing was tempered by the need to differentially share or protect the privacy of certain information as demonstrated by this quote from a participant in the same focus group session: “I was wondering why they put spiritual in there. That’s a very private thing. I don’t like seeing that in.”

Role of Family Members

This theme groups goals, information needs, and preferences for family members as characterized by HCPs and older adult focus group participants. HCPs perceived that family members have goals that differed from their own. This perception of differing goals also influenced the perceived level of detail necessary for decision-making by each stakeholder group and is illustrated by this quote from a HCP focus group 1 participant: “Family members just [want to] know overall: ‘Are they OK?’ They don’t necessarily need to know exactly what the deficit is as long as their overall health is OK, versus; we’re more concerned about detail.” HCPs also perceived that family members have different information needs than older adult patients. This quote from a HCP focus group 3

participant highlights a difference in the nature of communications with family members versus communications with older adults: “Family education is, I think, almost more important than patient information”. Older adult participants perceived that different families might have different desires to see the health information of their older adult relatives. When talking about interest levels with regard to seeing relatives’ health information, one older adult participant observed: “Some families ask and some families don’t. I don’t think you shove it at them.”

Discussion

Women were represented in greater numbers than men in both sets of focus groups. In the older adult focus groups, the uneven gender stratification can be explained by greater average longevity of women versus men. In the health care provider focus groups, the uneven gender stratification is likely due to greater representation of women in both nursing and geriatric health care professions.

The findings of this exploratory study suggest that health care providers believe that older adults place a high priority on social and spiritual wellness. Findings from the older adult focus groups did not necessarily confirm this view although some older adult participants stated a preference to protect the privacy of their social and spiritual information. The more obvious pattern that emerged was that the older adults in our focus groups discussed the goals of HCPs less frequently than HCPs and had less well-developed, less certain ideas about HCP goals and information needs. HCPs and older adults raised the issue of variation in the goals, information needs and preferences of different family members.

HCPs discussed their role as interpreting information to provide recommendations to older adults and their families. Older adults were interested in sharing certain information about themselves based on the situation and with whom they were communicating. HCPs stated that they were open to information from their patients. However, older adults generally perceived that bringing unsolicited information to HCPs might be an unwelcome move. As a result, support for each of the four aspects of wellness from the conceptual model that informed our original study[12,13] – cognitive, physical, social and spiritual - may be hindered in practice due to conflicting assumptions by HCPs and older adults about information sharing.

Mutuality, paternalism, and consumerism have been identified as possible outcomes in the patient-provider relationship based on patient and provider power[24]. Our findings suggest that HCPs attempt to achieve mutuality by acting as advisors when engaging older adult patients and their family members, but all stakeholders may benefit from a better understanding of the goals and information needs of the others. If health care providers, older adults, and their family members are to interact through consumer health informatics technologies to maintain wellness in older adults, larger studies to confirm that all participants have a practical understanding of the needs and goals of others are necessary to facilitate the design of tools that support these interactions.

Toward that goal we make the following recommendations:

- Identify new and existing types of health information that are useful to health care providers, older adults, family members, and other potential stakeholders.
- Identify and characterize the different types of older adults and family members who find consumer health informatics tools acceptable and the reasons why.
 - Describe how the goals, information needs, and preferences of older adults and family members change as their roles shift due to aging and changes in health status.
 - Explore ways to facilitate adoption of new consumer health informatics technologies by older adults such as making interactions with health information a pleasant experience, as in the example of “bragging rights” about good overall health included under Results.
 - Identify the reasons why some older adults perceive heightened risks to privacy and reluctance to share their health information to inform strategies to overcome barriers to technology adoption.
- Design standardized interfaces and tools that are easily tailored to individual patient problems and preferences so that health care providers can engage older adults and family members without being hindered by technology.
- Design standardized interfaces and tools that are easily learned by older adults and family members based on their goals and information needs.
- Develop communication strategies about the potential benefits of the use of consumer health informatics tools for all stakeholders.
- Develop communication strategies so that older adults and family members are clear about the information that health care providers find useful and are willing to use.

These recommendations are offered to place our findings in the broader context of communication practices and information use by different stakeholders. For instance, while the preferences of HCPs for certain types of information may seem obvious based on the questions they ask, an older adult patient might feel reluctant to bring alternative sources of information if they are not explicitly mentioned. Discussing new types of information may also contribute to discussion of the types of information that are preferred by individual stakeholders.

One motivating factor for this effort was to address the gap in knowledge about the information needs of older adults and other stakeholders to inform design of consumer health informatics technologies[9]. The emphasis of this study on people rather than information systems is consistent with the modern tradition of information behavior research[25,26]. The results of this study contribute to a body of knowledge that may help connect information behavior theory and information system design practice as called for by prominent information behavior researchers[26].

Limitations

Due to the single community of residence, our older adult participants were of a higher socio-economic status and educational background than the general population. Thus, results from this sample may not generalize to wider populations of older adults. Our HCP participants were drawn from one region of the United States and represented the disciplines of medicine and nursing. Other HCPs, such as occupational therapists or pharmacists, from different regions or countries, may have different information needs. Thus, results from this sample may not generalize to allied health providers on a national or international level. Finally, while family members who assume an informal caregiving role were recognized as key stakeholders by both older adults and HCP participants, they were not included in this study. The needs and goals of these family members should be examined in depth as well.

Conclusion

Understanding how the perceived information needs, goals, and preferences of HCPs, older adults, family members, and other potential stakeholders compare is important to design for usability and to facilitate adoption of new consumer health informatics technologies. Patient-provider interactions for shared decision-making could be enhanced with flexible tools designed to manage subjective, self-reported measures of social and spiritual wellness in addition to objective cognitive and physical measures. To inform design of these tools, larger studies are needed to characterize the goals, information needs, and preferences of all stakeholders who interact with the health information of older adults. To maximize adoption and benefits to all stakeholders, these types of tools may need to be introduced by health care providers so that older adults view them as trustworthy and useful to maintain wellness.

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