Persona Development and Educational Needs to Support Informal Caregivers

Zeina AL AWAR and Craig KUZIEMSKY

Abstract. Informal caregivers are playing an increasing role in community based care delivery. Research is needed that looks at the educational needs of informal caregivers as a precursor to HIT design to support community care delivery. A challenge is informal caregivers have very diverse educational needs. Personas are an approach to describe user characteristics as part of systems design and this approach could be used to understand and categorize the various educational needs of informal caregivers. This paper addresses this research need and provides a method for persona development and the identification of educational needs for informal caregivers.

Keywords. Persona, informal caregiver, health education, tailoring

1. Introduction

As more care delivery is provided in community settings there is a need for the development of health information technology (HIT) to support care delivery outside traditional settings. The first step in designing HIT is identifying user requirements. The patient participatory medicine movement has led to an increase in applications designed to support patient led care delivery. Informal caregivers, such as family members or friends, are also playing an increasing role in community based care delivery. However, informal caregivers often struggle and feel insecure in their role [1]. Informal caregivers have substantial information needs as part of providing care but, to date, there is little research that has looked at the educational and information requirements of informal caregivers [11]. To overcome that shortcoming, we need interventions that support caregiver competence, preparedness, and confidence while providing care delivery [1]. These interventions must be based on evidence and designed to implement interventions for informal caregivers based on an assessment of their needs [2,3]. Informal caregivers have such vast needs that one size fits all solutions cannot be used but rather HIT solutions must be tailored to the specific needs of different types of informal caregivers. As a first step to HIT design, we need research that explores caregiver educational and care delivery needs.

While we cannot design HIT to support every context of a user group, we can design to support defined subsets of users. One such way of doing that is to develop user personas, described as “structured ways of typifying a group of users in text and pictorial formats.”[4]. Personas describe user characteristics that go past mere demographics by capturing the mental processes users employ, including their

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1 Corresponding author, E-mail: kuziemsky@telfer.uottawa.ca
expectations, prior experiences, and projected behaviour [4]. A persona is typically based on a narrative that specifies the goals that a fictional but representative user has for using an artifact, while also describing their environment, qualification, attitudes, and the tasks they need to accomplish.

While personas are a valuable way to define and shape requirements for end users, there is a need for papers that present approaches for developing personas [5]. A particular need is for persona developers to understand the various educational needs of informal caregivers [5]. This paper addresses this research need and provides a method for identifying education needs and developing personas to support the delivery of educational needs to informal caregivers.

2. Materials and Methods

2.1. Data Sources

Two data sources informed the study. First, we conducted 8 semi-structured interviews with eight informal caregivers. Three of the interviews were in person and five were conducted via telephone. Five of the participants were female and three were male; their ages ranged from 38 to 70 years. All were either related or married to their patients. The questions were designed to capture the experiences of the participants and then use them to derive their unexpressed needs.

Second, a nursing focus group was also conducted with four nurses with experience caring for palliative cancer patients in a home setting. The focus group protocol was also semi-structured and open-ended, and the participants discussed their experiences caring for palliative patients and dealing with their informal caregivers.

2.2. Data Analysis

Qualitative content analysis focused on coding and extracting themes from the data collected in the in-depth interviews. Our analysis had two goals. First was to develop user personas. Participant characteristics were laid out in table format and used to derive user personas using Miles, Huberman, and Saldaña’s recommendations for making inferences from data matrices [6]. Characteristics extracted from the interviews to determine the individual background and circumstances of each participant were mapped out on a spreadsheet. The spreadsheet was then analyzed for patterns that identify the differences in their caregiving needs following a set of recommendations for making inferences from matrices, including observing patterns and themes, making comparisons and contrasts, clustering, and making and verifying explicit conclusions [6].

Our second goal was to understand the educational needs of informal caregivers to identify how they differed according to the personas. Educational needs were identified using the Needs Assessment design [7], which articulates user experiences as a prerequisite to identifying their needs. We studied caregiver needs according to three categories of needs from the Needs Assessment design [7]: Take-It-for-Granted Needs, which are the minimum expectations of a service, Typical Wants, which are attributes that end-users watch for and assess, and Attractive Needs, which are those that the end-user is usually completely unaware of having.
3. Results

3.1. Caregiver Personas

Persona characteristics extracted from the interviews were mapped out on a spreadsheet to determine the individual background and circumstances of each participant. Upon examining the caregiving habits and the expressed needs of the interview participants, no difference was noted among different ages, genders, geographical settings, or educational levels. Furthermore, the level of comfort with computer technology did not seem to affect their information-seeking habits, as every one of the participants used technology to search for information related to their caregiving role at one point during their care delivery. From our data analysis we identified the level of illness of the patient being cared for and the level of caregiving intensity as two key dimensions to structure personas.

The patient’s illness level directly influences their functional status and their care needs, often dictating the information needs of the caregiver [8]. The second version of the Palliative Performance Scale (PPS) [9] was used to estimate the functional and performance level of patients cared for by the interview participants. PPS assigns a score in percent increments of 10 with 100% being full ambulation and self-care, 60% having reduced ambulation and some assistance need, and 20% being bed bound with total caregiving needed. Transcripts were re-examined and a new column was added to the spreadsheet to assign a PPS score to each patient. We grouped patients into 3 PPS categories – 50-60%, 30-40% and 10-20%, as each category represents distinct caregiving needs. People with a PPS score of 70% and above are fully functional and do not require a caregiver.

Caregiver intensity was defined using the values set by Jacobs, Laporte, Van Houtven, & Coyte 2014 [10]. A new column was added to the spreadsheet to assign a category to each participant. Participants were considered less-intense caregivers if they provided less than 5 hours of care per week, mid-intensity if they provided 5-15 hours of care per week, and high intensity if they provided 15 or more hours of care each week [10].

Table 1. Five persona categories according to caregiving intensity (vertical axis) and Palliative Performance Scale Version 2 (PPSv2) (horizontal axis)

<table>
<thead>
<tr>
<th>PPS</th>
<th>10-20%</th>
<th>30-40%</th>
<th>50-60%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;5 hours/week</td>
<td>LILN</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-15 hours/week</td>
<td>MIHN</td>
<td>MIHN</td>
<td>MILN</td>
</tr>
<tr>
<td>&gt;15 hours/week</td>
<td></td>
<td></td>
<td>HIAN</td>
</tr>
</tbody>
</table>

Table 1 shows the five categories of personas we developed: Less-intense low-need (LILN) caregiver, Medium-intensity low-need (MILN) caregiver, Medium-intensity intermediate-need (MIIN) caregiver, Medium-intensity high-need (MIHN) caregiver, and High-intensity All needs (HIAN) caregiver. Those with a score of 40% and below all needed a caregiver with a level of involvement greater than 5 hours per week. Only one high intensity category (HIAN) was created as high-intensity
caregivers were defined by one role where the caregiver would take care of all patient care needs. This is especially prevalent among caregivers of unstable patients, who could be high need one day and intermediate or low need the next day.

3.2. Informal Caregiver Educational Needs

In the second part of our analysis we identified informal caregiver educational needs according to four categories: Presentation, implementation, practical caregiving and information. The categories started through deductive codes [e.g. 12-13] that were then extended through inductive codes from our data analysis. Presentation refers to how information is presented to the end-users. Implementation referred to the way information and recommendations can be incorporated into the daily life of the end-users and the policies of the health care system under which they live. Practical caregiving is the caregiving components that deal with patient care issues including emergency measures, equipment, medication management, mobility, nutrition, pain, and physical symptoms. Information deals with the clinical information that informal caregivers need to understand including different aspects of the patient’s illness, treatment options, available resources, and complications to be expected such as functional decline. Information on functional decline was one of the key attractive (i.e. unexpressed) needs from participants.

3.3. Differences in Caregiving Needs by Personas

After determination of the informal caregiver needs as discussed in the previous section, the next task was to discover how the five personas differed from each other with respect to caregiver needs. While the categories of caregiver needs were consistent across the personas, the operationalization of needs differed. The biggest difference among the different personas was in the practical caregiving category. When patients transition from low into medium and high intensity categories, their medication regimen increased significantly, and thus medication management (e.g. medication logs and information on drug-drug interactions) became a priority need. Further, as caregiving transitions from low into medium intensity, functional decline of the patient becomes more significant and information (e.g. symptom onset and management) and tools (e.g. equipment) to understand and support a patient in decline becomes a priority need. The different caregiving needs and how they must be presented to support different personas become the basis for HIT requirements. For example, as patients become less mobile in the medium and high intensity personas, videos and other instructional tools for supporting mobility and transfers would be an HIT requirement.

4. Discussion

This study presented an approach for developing caregiving personas as a means of identifying and structuring educational needs as a precursor for HIT design. Our approach extends existing work on personas in two ways. First, while existing research on personas has been based on one dimension (i.e. geographic) our personas are based on two dimensions (caregiving intensity and the functional and performance level of the patient). Second, our personas emphasize different caregiving experiences and the ways that caregiver needs changed over time. One novel feature of our persona
development approach is that it allows for the determination of caregiver needs within a persona at a specific period of a patient’s illness, but it also supports the descending transition into subsequent personas with additional and/or more sophisticated needs than the previous persona.

Our next step is to use the personas and information needs to derive requirements for the design and evaluation of a prototype HIT to support informal caregivers. The educational needs we identified (e.g. information, practical caregiving) will be converted to system design requirements. A limitation of this study is that we have only developed personas for one very specific group of caregivers. Testing our personas and caregiver needs in other settings and caregiver groups is also future work to be done.

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References


