

Lived Experience, Stakeholder Evaluation and the Participatory Design of Assisted Living Technology

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Abstract. This paper presents the theoretical and methodological framework underpinning the advancement of new technology enabling seniors domicile in residential homes to live with independence, quality of life and dignity. In addition, it presents the preliminary findings of this research including the emerging user interface design solution.

Keywords. Ageing, assistive technology

1. Introduction

Successful aging is multidimensional encompassing the avoidance of disease and disability, the maintenance of high physical and cognitive function, and sustained engagement in social and productive activities [1]. Psychosocial models focus on life satisfaction, social participation, functioning, and psychological resources [2, 3]. According to biopsychosocial models of health and well-being, medical and psychological factors, family and social factors are some of the different determinants impacting on a person's health and well-being [4, 5].

Residential care/nursing homes provide 24 hour care to seniors. Residential care facilities have historically addressed societal goals (for example, freeing up hospital beds, taking burdens off families, coping with poverty amongst elderly), as opposed to addressing the needs of those domicile in them [6].

Recently, there has been a move towards relationship centered care [7 - 9]. Advocates of relationship centered care emphasize the importance of nurturing personhood and positive social relationships. As human beings are active relational beings, nurturing positive relationships is essential to well-being, and has a bearing on health care experiences and outcomes [10].

New digital devices allowing self-tracking of health and associated parameters (i.e. activity/fitness, sleep and diet) are gaining popularity [11]. This 'self-monitoring' approach (referred to as the 'quantified self' movement) has the potential to change and/or is changing both how health and health care delivery is managed, and how health related information is stored and shared. In addition, new technologies are being

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advanced to support the needs of seniors living both independently and in assisted living contexts. Generally, this involves the use of a range of connected devices (i.e. TV, tablets, smart phones, wearables and environmental sensors).

2. Methods

2.1. Overview

This is an action research study combining several qualitative research methods including ethnography (interviews and observations) and participatory design [12]. Overall, the human factors design approach is premised on the assumption that solutions for seniors and other actors are necessarily interrelated. As such, a stakeholder evaluation based approach is adopted [13]. Human factors research involves active and ongoing participation of end users (i.e. seniors) and other key stakeholders. As detailed in Table 1 below, system development follows several iterative activities pertaining to (1) needs analysis, benefits analysis and requirements elicitation, (2) user interface design prototyping and (3) evaluation. Certain research phases are sequential (phases 1 and 2), while others are running in parallel and are iterative (phases 3, 4, 5 and 6).

Table 1. Research Phases & Activities

| Research Phase | Research Phase/Activity | Stakeholder Involvement |
|----------------|---|------------------------------------|
| 1 | Literature analysis | Internal stakeholders |
| 2 | Preliminary definition of philosophy/approach, concept, high level requirements and associated personae specification | Internal stakeholders |
| 3 | Requirements elicitation (interviews and observations with end users and stakeholders) | External stakeholders |
| 4 | Elaboration of concept and philosophy and specification of detailed requirements and personae | Internal stakeholders |
| 5 | User interface design prototyping | Internal stakeholders |
| 6 | Co-design and evaluation | Internal and external stakeholders |
| 7 | Final specification and design | Internal and external stakeholders |

In relation to needs analysis, interviews and observations are being undertaken with end users (n=20) and other stakeholders (n=15). The methodological approach is underpinned by phenomenological approaches to eliciting information about ‘lived experience’ [14, 15] and specifically, interpretative Phenomenological Analysis [16]. The emphasis is on understanding the context and meaning of experience, and in particular, the interactions between seniors and relevant stakeholders in their personal and professional community (i.e. family members, carer’s, friends, GP and specialists).

In relation to participatory design activities, the methodology draws upon person centered design approaches – specifically, ‘personae based design’ [17], and ‘Scenario Based Design’ [18]. Personae’s have been advanced for seniors in different contexts.

This ensures that the proposed technology is cognizant of: (1) the experiences and needs of end users in different settings and situations (i.e. lifespan perspective – home, assisted living community and residential homes), and (2) the specific needs of end users and other stakeholders in the residential care context.

Bowties are being used to elicit and validate technology requirements in relation to addressing latent conditions and states/benefits to be achieved. Specifically, bowties enable joint problem solving concerning user need/requirements and design solutions. Co-design activities focus on how the proposed technology installs barriers to (1) prevent the event from occurring and (2) to recover the situation, if the hazard encountered (thereby reducing/mitigating the consequences of the hazardous event). The qualitative data analysis software NVivo is being used to support the thematic analysis of data relating to lived experience and need. Following, the analysis of all data, co-design activities will be undertaken with the participant panel.

2.2. Community of Practice & Participant Profiles

In support of stakeholder design/evaluation activities, a ‘Community of Practice’ (COP) [19] has been formed comprising both internal and external stakeholders. Both internal and external stakeholders participate in different research activities. Internal stakeholders (N=10) include members of the assisted living project/research team (i.e. human factors researchers, user experience designers, developers, product owners, nurses and experts in health informatics). External stakeholder comprises two participant groups (1) end users and (2) other stakeholders (N = 30 to 40 participants). End users are split into four sub-groups – comprising seniors living independently and living in residential homes, potentially living with one or more morbidities, with different levels of functional and cognitive ability and an age range of between 60 to 90 years. Other stakeholders include three sub-groups, (a) family members, (b) formal aged care staff – (i.e. aged care nurses, care assistants and community nurses) and (c) other stakeholders (i.e. GPs, geriatricians, experts in ageing, volunteers in active ageing groups and volunteers/staff of relevant groups/societies). End users and other stakeholders are participating in research phases 3, 6 & 7.

2.3. Summary of Research to date

To date, twenty interviews have been undertaken with various stakeholders. This has included older people living independently, aged care nurses, family members, volunteers and experts in ageing and dementia. Over the coming months, additional field research will be undertaken at a post-acute care community unit, and at a nursing home. This second phase of field research will involve the participation of patients, nursing home residents and nursing/care staff.

3. Results

3.1. Ageing

In relation to seniors, participants noted an increase in social activity and engagement in their late fifties/early sixties (i.e. pre-retirement and/or once their children had left

home). Loss of a spouse was the most impactful experience in later years. Second to this, is the experience of decreased health and/or reduced mobility. Consistently, participants reported loneliness following the loss of a spouse/loved one, and the need to participate socially, to mitigate losses in relation to companionship. There was general agreement across different stakeholders that independence for seniors is linked to interdependence. That is, independence for seniors necessitates support from other actors in an older person's personal and professional community. Participants noted an increased need for help in the home. This includes informal help from family members, friends and neighbors, along with assistance from care staff contracted from public health service agencies and/or privately contracted.

3.2. Perceptions of Residential care

Overall, participants expressed a strong preference in relation to remaining in their own homes. Daily routines were reported as closely bound up with '*being in their own home*' and '*having access to their own things/furniture*'. Also, the home was reported as a place closely associated with memories and personal identity. Moreover, there is a perception of '*being in charge*' in one's own home. Overall, participants expressed concerns/fears in relation to transitioning to a residential home. Consistently, this was reported as something to be '*put off*' until '*it becomes inevitable*'. Further, it was reported that it might be easier to transition to residential care after an intensive period of hospital care (i.e. acute position). Research indicates a general perception that residents often decline rapidly on transitioning to nursing home environments. This is attributed to a lack of independence, loss of purpose, reduced activity and poor social participation. Overall, there was a perception that given staffing/nurse workload issues, there are difficulties delivering personalized care in residential care environments. As stated by one participant, '*Staff are doing their best – but there is never enough time*'.

3.3. Relationship centred care and stakeholders

Concepts of 'relationship centred care' resonated both for older people, family members and those involved in care delivery. It was agreed that in the residential care setting, the proposed stakeholders for new assisted living technology might include residents, family members, nurses, care assistants and administrative staff (i.e. staff working in admissions and involved with co-ordination with family members). All such actors might benefit from this technology – specifically, in relation to monitoring the resident (i.e. tracking health status, activity, mood, pain), and addressing individual needs on a real-time basis. In nursing homes, many of the residents have early cognitive decline and/or dementia. As such, their ability to interact with tablet systems is limited. However, participants noted that the advancement of solutions for other actors (i.e. administration, nursing and care staff along with family members) would be beneficial for residents with Dementia.

3.4. Lived Experience, States and Benefits

Successful ageing is multidimensional and includes psycho-social elements. In relation to seniors, this research outlines several states to be (1) promoted, (2) managed and/or mitigated and (3) avoided. For more, please see Table 2 below.

Table 2: Lived Experience, States & Benefits

| Promote/Support | Manage, Mitigate & Reduce | Avoid |
|---|------------------------------------|---|
| Quality of Life | Loss of identity | Deception |
| Wellness | Loss of privacy | Infantilization |
| Independence | Loss of physical liberty | Elder abuse |
| Social Participation | Physical discomfort | Objectification of the dementia patient |
| Privacy and protection of personal sphere | Communication difficulties | Unsafe behavior |
| Communication | Fear | Reduction in human contact |
| Safety | Boredom | Neglect |
| Ability | Sense of powerlessness | |
| Identity | Difficulty with new information | |
| Empowering Person | Difficulty with change | |
| Dignity/respect | Restlessness | |
| Purposeful living | Feeling lost | |
| Active and healthy living | Overstimulated | |
| Sense of community | Stress | |
| Sense of belonging | Apathy/loss of interest | |
| Sense of purpose | Wandering | |
| Sense of usefulness | Frustration | |
| Acceptance | Confusion | |
| Resilience/coping | Agitation | |
| Self-management of health | Negative thinking | |
| Calmness | Depression | |
| Engagement | Aggression/Anger | |
| Sense of confidence in own ability | Sleep disturbances and sun downing | |
| Awareness (including sensory awareness) | Suspicious and delusions | |
| Nurturing person | Self-neglect | |
| Citizen participation | | |

3.5. Stakeholder Need & User Requirements

Participants observed that such technology might be useful in relation to keeping residents both active and engaged. It was noted that future technology might enable residents to maintain social connections and ‘*keep in touch with family and friends*’. This was distinguished from ‘*providing companionship*’. A tablet solution can afford the opportunity to make a telephone or video/Skype Call. However, it cannot replace the lived experience of ‘*being in a relationship*’ and/or ‘*the company of family and friends*’ and associated communications/supports. The application of passive technology to monitor resident safety, prevent falls and raise alarms (if needed) was welcomed by all (i.e. passive sensors in beds and activity monitoring sensors). Further participants noted that they wander management technology (i.e. door sensors and sensors in the environment), would be acceptable, if this meant that they could move around freely in a nursing home. Participants noted that they would not like instructions/prescriptions from a piece of technology in relation to lifestyle choices, diet/exercise and social engagement. Having said that, it might be useful to view information about events, obtain medicine reminders and exercise prods, and/or participate in interactive physio exercises. Overall, this might ‘*help keep a person engaged*’ and ‘*give some purpose to the day*’. Participants liked the idea that from a resident perspective, much of the technology might be happening in the background (i.e. bed sensors, sensors on windows/doors etc). Further, the Tablet might provide

simple/fast access to a small number of functions that are meaningful to seniors (as opposed to unnecessary noise). In this regard, participants stated that a level of realism in relation to proposed functionality is required. Functionality such as ordering a meal, enabling access to entertainment functions (radio, TV), enabling the provision of feedback about mood/pain, supporting communication and the provision of access to photos/videos of family is useful. In addition, technology to support stress management and relaxation (automation of music at specific times, providing easy access to preferred TV stations/programs) is beneficial. Functionality to support self-management of health (education, access to medical records) might not be used. Further, participants highlighted the importance of the resident's admissions process in terms of (1) eliciting information about the resident (i.e. who they are, what matters, circle of care) and (2) enabling a smooth transition to their new environment. Moreover, as part of the admissions process, participants might obtain training in relation to the use of the tablet. Moreover, during the admission process, tablet menu options and technology functions might be customized based on resident preferences and what is meaningful and realistic for them.

From a nursing perspective, future systems might address issues around assessing patient acuity and enabling easy and real-time access to resident information (i.e. health status and electronic health records) and management of patient medication. Electronic rounding systems might present patient well-being information (i.e. level of physical activity, pain, sleep, diet and social activity), elicited from resident self-reports, ambient sensors and from care assessments. For carer's and family members, systems should support care and activity/safety monitoring tasks, along with enabling empathy and social connection. It was noted that although promoting contact with family members is good, this technology cannot mitigate negative family relationships. Further, it was noted that resident GP's and/or GP's working for the nursing home, might have access to patient information.

3.6. Emerging Concept & Provisional Design Solution

Overall, the concept is to develop a range of self-decided services (opt in/out), based on what matters to older people, and to allow for personalization. The proposed functionality is (1) conceptualized in relation to stakeholder relationships. According, a suite of interrelated technologies is being advanced for seniors and other stakeholders (i.e. nurses, care assistants, admissions/administration personnel, family members, GP etc). The proposed technology (2) addresses all three pillars of well-being and the interrelationship therein. Specific functions promote wellness and map to the underpinning biopsychosocial model of health and well-being. Further, the functionality takes into account (3) models of successful ageing - supporting social participation, addressing stress, mood and engagement, providing entertainment functions and promoting self-management and purposeful ageing. Further, (4) the availability and level of personalization reflects an 'ability' philosophy.

The design solution is adaptive in terms of age-related changes and characteristics, and avoids known problems with current WIMP (windows, icons, menus, point-and-click devices). Interactions are natural using touch (and potentially speech and gesture). Currently, outputs are text/image based. Research is currently addressing multimodal aspects (i.e. voice synthesis and haptics).

The admissions user interface is conceptualized in terms of a series of steps to promote familiarization for both residents and care staff, and reassurance for residents and

family members. The resident solution is customized in relation to resident need and ability. The nursing solution promotes meaningful interaction with the resident, based on a real time picture of the resident's state, and background information about who the resident is and what matters to them. A concierge user interface supports management of resident requests (i.e. travel, room maintenance etc).



Figure 1: Resident Screens

3.7. Ethics

Future systems should not be used to replace person centred care and/or to reduce the time that nursing and care staff spend with their patients. Such systems should respect a senior's privacy and choice (i.e. option to opt in/out of sensors). Residents should have control over their personal sphere, including any information captured about the biopsychosocial dimensions of their health and well-being.

4. Discussion

Relationship centered care provides the conceptual framework for thinking about need, and associated concepts of independence and quality of life. Overall, the approach is to develop technology from the perspective of understanding the relationship/interdependencies between different stakeholders. These interdependencies are modelled in terms of workflow and user interface design, so that the states/lived experience outlined in Table 1 are realized.

In a residential context, technology has a role beyond that of (1) managing and reporting on a resident's physical health and security (and associated clinical and care tasks), and (2) supporting operational and organisational goals (i.e. staffing, risk management and compliance). Technology has a role in terms of supporting the well-being of both patients and staff alike, enabling life/job satisfaction and social participation, and fostering an environment that provides a sense of purpose for all (i.e. residents, staff and families). It is not likely that mid to late stage memory care patients, will have significant interaction with Tablet/TV systems. Here the focus will be on delivering smart and emphatic solutions for both carers' and family. Critically, solutions for these actors will yield benefits for memory care patients.

Technology is only one part of the solution, and does not replace person centred interaction/care. Further, the implementation of new assisted living technology needs to take into account other socio-technical dimensions (i.e. people, process, environment,

culture and training). Relationship/patient centered care requires more than technology. It necessitates happy well trained staff, working with the right level of resources (i.e. staffing, equipment) and supported by person friendly processes that foster communication, trust and open disclosure.

5. Conclusions

There are need/benefits on different sides. Evidently, supporting resident autonomy, independence and quality of life is important. However, such autonomy cannot be conceptualized outside an understanding of the partnerships seniors have in their personal and professional community. Independence (and quality of life for seniors) is linked to interdependence. Accordingly, the approach is to develop technology which promotes resident ability and is premised on supporting the relationships between different stakeholders.

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