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Independence and Shared Decision Making: The Role of Smart Home Technology in Empowering Older Adults

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Abstract— **This study aims to explore the concepts of independence and shared decision making in the context of smart home technologies for older adults. We conducted a Delphi study with three rounds involving smart home designers, and researchers as well as community dwelling older adults. While there were differences in the way different stakeholders define these concepts, the study findings provide clear implications for the design, implementation and evaluation of smart home applications.**

I. INTRODUCTION

Smart home applications are installed in a residential setting utilizing sensor or other passive monitoring technologies with the goal to improve quality of life and overall well-being of their residents by monitoring their activities, detecting emergencies and identifying trends or deviations from expected patterns. The purpose of this study is to *determine the defining characteristics of independence and shared decision making* as perceived by distinct groups, smart home designers and researchers as well as community dwelling older adults. These characteristics will inform guidelines for the design and implementation of smart home applications.

II. BACKGROUND

A. Independence

Many definitions of independence in the literature focus on functional limitations associated with disability and/or aging. Most published studies define independence as it pertains to the ability to perform activities of daily living (ADLs) and overall functional status [1-4]. In this context, the issue at hand is individuals' ability to perform ADLs such as bathing, dressing, walking, and transferring on their own. In some cases, researchers have additionally included instrumental activities of daily living (IADLs) such as meal preparation, shopping, housework, and phone use, as part of the definition of independence [3, 5]. The advantage of founding the concept of independence in levels of functional status and specifically ability to carry out activities or tasks, is that existing instruments can be used to quantify and assess independence; the disadvantage, however, is that the sole focus on functional ability does not capture the entirety of what is commonly understood or perceived as independence.

Falter, Gignac and Cott [6] expand the definition of independence to include not only domains such as mobility, personal care and household activities but also community mobility and valued activities. Similarly, Brach and VanSwearingen [7] concluded in their descriptive study that independence is defined not just by physical function but also by the ability to remain community-dwelling.

Elsner et al. [8] conducted case studies of three centenarians where independence was conceptualized in a hierarchical structure where the higher-level needs included social needs (such as closeness and personal contact) whereas the lower level related to material needs such as safety and security [8]. Baltes and Wahl [9] defined older adults as independent if they were able to take care of themselves and were constructively engaged (examples of constructively engaged behaviors include reading, writing, playing a game). Hazuda et al [10] equated the promotion of independence to preventing disability and identified several forms of adaptations to maintain independence: physical, cognitive, affective, social and environmental.

Potter [11] defines independence for people with disabilities as individuals' control over their life including management of personal affairs, decision making, and maintaining a social role as part of the community (Potter, 1996). Ward-Griffin et al. [12] described striving for independence as being in conflict with older adults' perceived need to exercise caution in order to prevent injury. According to Ward-Griffin et al. [12] the outcome of striving for independence is the promotion of autonomy. Their study involved older adults who had recently suffered falls or who had a fear of falling [12]. Study subjects described the following strategies to promote their independence and autonomy: minimizing the impact of the fall, use of assistive devices, resisting confinement, acknowledging the risks involved in activities, and using resources.

Falter et al. [13] concluded in a study of the relationship between disability and independence in older adults with chronic obstructive pulmonary disease (COPD) that this relationship depends on the nature of the activity and is influenced by factors that are amenable to study and

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intervention. In particular, the vast array of behavioral strategies available to older adults with COPD enables them to feel highly independent despite disability [14]. Koehler [15] developed a theory that identifies three properties of protecting independence: (1) maximizing health; (2) managing illness episodes; and (3) reflecting on the eventuality. While these studies indicate a complex underlying framework for independence, in other cases the meaning of independence is related to a single variable, namely living alone [16,17].

It becomes clear from this review that numerous researchers aim to promote independence by targeting individual deficiencies and aiming to change them, whereas others follow a paradigm by which the "problem" to be treated lies within environmental barriers rather than within the individual. While many studies define independence in relation to activities of daily living, other researchers argue for inclusion of additional psychosocial components under such a theoretical framework. There is neither consensus in the literature about the meaning of independence nor is there a detailed conceptual model of independence as it relates to people with disabilities and/or older adults. This can be problematic as policy makers, system designers and technology vendors focus on smart home applications to increase independence while the term may actually carry different meaning to the different professional groups.

B. Shared Decision Making

The empirical evidence that involving patients and in our context, older adults, in healthcare decisions makes a significant and enduring difference to healthcare outcomes [17-20] is not unequivocal, although there are some studies that support this hypothesis. One difficulty (among many) is that the involvement of patients in decisions has been left undefined. It is usually conceptualized as patient centredness [20, 21], which is a broad and variably interpreted concept that is difficult to assess using current tools [22-23]. Nevertheless, the ethical need to respect autonomy and respond to older adults' desire for more involvement in decision making is becoming widely recognized [24-26].

Charles et al [27] present a treatment decision-making framework based on information exchange, deliberation about treatment options, and agreement on the treatment to implement. Within this framework, three approaches are presented to label the process and outcome of decision-making in this context [27]:

-The *pure paternalistic approach* is characterized by health care provider control whereby the provider determines the amount and kind of information that is given to the patient. There is unidirectional information flow. The provider deliberates about the benefits and risks of available options and reaches a decision without patient input [27].

-The *pure informed approach* is characterized by a division of labor and the preservation of patient autonomy. The provider makes information on treatment options, challenges and risks available to the patient. The patient assesses the situation in the context of her own value system and preferences and makes a treatment decision [27].

-The *pure shared approach* is characterized by ongoing interaction and information exchange between patient and provider in all stages of the decision making process. There is bidirectional information flow. The provider offers information about all available options and risks and the patient discusses personal preferences, their value system, lifestyle and personal preferences. The decision making process includes an extensive discussion and negotiations in search of the best option to pursue. The decision making process is a dynamic one where both providers and patients may shift away from their initial position [27].

Shared decision making is increasingly advocated as an ideal model of treatment decision-making in the clinical encounter. In the shared model, the process by which the interaction is conducted aiming to reach an agreement can be determined at the outset of the encounter or develop as the encounter unfolds and is shaped dynamically by the ongoing communication. Information sharing is a prerequisite to shared decision making.

It is a challenge to expect all patients to enroll in this process as equal partners as one may argue that there may often be a power imbalance in the provider-patient relationship. Obviously health care providers have superior knowledge of the options and issues involved as well as clinical experience and therefore join the process as experts [28]. A patient may often participate in the encounter feeling vulnerable due to their illness or fear of the unknown. Additional issues such as health literacy, income, gender, cultural barriers may impede patients and prevent them from expressing their preferences or negotiate with the physician [28]. As Guadagnoli and Ward point out, it is a challenge for providers who want to practice a shared approach to provide a safe environment for patients allowing them to be comfortable in exploring information, and negotiating options [29].

The era of smart homes introduces not only new ways to monitor residents but also new data sets that can be made easily available to residents themselves, their providers and other parties. Shared decision making can be supported by the availability of extensive data sets if stakeholders find the smart home output to be useful and easy to use. While many smart home applications imply or allude to a potential empowerment of their residents facilitated by the availability of new data that are accessible to the residents themselves, the actual process of empowerment and whether such platforms facilitate shared decision making have not been studied yet.

III. METHODS

A. Literature Review

We conducted a systematic literature review of studies focusing on independence. We have searched computerized databases of English language articles (MEDLINE, CINAHL, PsycINFO and Healthstar) on the term independence. Resulting articles were reviewed and included studies focusing on the concept of independence for older adults (including both data-based studies and conceptual or theoretical papers). We excluded articles that did not specifically address independence as one of the article's primary concepts or foci. Additional citations were identified from key references in the reviewed articles.

Based on the review of the resulting 42 studies, we created an exhaustive list of all defining characteristics or dimensions of independence. This framework follows a holistic view that captures independence as a state in which older adults maintain, adjust and process resources (financial, physical, social and other) within a given environment in order to maximize ability for self-care, control and perception of identity.

When examining an individual's independence, there are a series of external attributes (such as the availability of financial resources, accessibility to health care services, the broader environment and the social network of an individual) that influence that individual's self-identity and independence. In addition, a series of internal attributes (an individual's functional capabilities, their health status, cultural profile and background and overall attitudes and perceptions towards services or interventions) influence self-identity and independence. In this context, technology assumes a mediating function as a tool that can support or enhance the individual attributes.

B. Delphi Study

We conducted a Delphi study asking smart home designers and researchers as well as community dwelling older adults to identify smart home features that would support independence and shared decision making for older adults.

Smart home designers and researchers who are members of the International Medical Informatics Association (IMIA) Working Group on Smart Homes and Ambient Assisted Living sent an electronic invitation to participate in an online survey for *Round 1*. Respondents were asked to supply the descriptive words or phrases they considered representative of the concepts of independence and shared decision making in the context of technology use.

The results of the analysis led to the instrument used for *Round 2*. This instrument included all identified characteristics from Round 1 and the literature review accompanied by a 5-point Likert scale to be rated as inappropriate, minimally appropriate, somewhat appropriate, appropriate and very appropriate. Respondents had the opportunity to make note of additional characteristics if they felt these are missing as well as additional comments.

The *Round 3* instrument provided feedback to the respondents as to the means and standard deviations of each of the items. Respondents prioritized operational definitions for each of the characteristics included in this round. Another task for respondents was to supply data from their client population and/or research subjects pertaining to the prevalence of independence according to age group, gender, and race and suggestions how technology can support some or all of the defined characteristics of independence and shared decision making.

A similar approach with a Delphi study including three rounds and focusing on independence and shared decision making in the context of technology use was implemented to assess older adults' perceptions. Participants were identified in independent retirement communities, online communities and through convenience sampling among community dwelling older adults in the Northwest.

The Delphi technique optimizes the use of group opinion whilst minimizing the adverse qualities of interacting groups. Its main features include structured questioning, iteration, controlled feedback and anonymity of responses. Structured questioning takes place via surveys. Iteration allows the questionnaire to be presented over a number of rounds to participants enabling them to reconsider their responses. Controlled feedback is achieved by aggregating responses and providing feedback to the whole group for their reconsideration. Thus, all responses are taken into account. Anonymity gives participants the freedom to express their opinions without feeling pressured by the entire participant group.

IV. RESULTS

A total of 53 researchers, system designers and experts and 48 community dwelling older adults participated in the Delphi study. Findings indicate that there are differences between the two groups (designers and researchers on one hand and older adults on the other) in the way both independence and shared decision making are defined. Shared decision making was interpreted primarily as linked to patient education in the former group whereas it was defined as an active and empowered role in the decision making process for the latter group. Implications for smart home design resulting from the Delphi study rounds include the importance of control that enables users to determine when they are being monitored and who to share data with. Additional elements include the concepts of choice, informed consent, ongoing feedback. It became clear from both groups that smart home technology should not be introduced to support or maintain a paternalistic approach where older adults are monitored without knowing where or why and not being able to determine the features, purpose and function of smart home elements.

Several older adults stated that they would not welcome a disempowering approach that would be facilitated by tools installed in their own residence. Unlike technology installed in the outpatient setting, smart home technology is introduced into one's private sphere and may affect their self perception, quality of life, and interaction with others. Shared decision making was perceived as significant not only as it pertains to decisions about treatment options during a clinical encounter but also decisions about what technology to use when and how frequently, who should have access to the resulting datasets and under what conditions.

V. CONCLUSION

Independence is a concept that drives policy making and design of clinical interventions. The focus on independence is evident in federal initiatives; the US Administration on Aging, Department of Health and Human Services introduced within the reauthorization of the Older Americans Act a proposal to pilot "Choice for Independence", a demonstration project to promote consumer-directed and community-based long term care options. This program aims to strengthen the nation's capacity to promote the dignity and independence of older people.

Independence level has also been linked to requirements of care and the need for institutionalization. However, very little work has been done to analyze the concept of independence and define it as a theoretical construct. As smart home technology is often designed with the aim to increase independence, this study provided insight into this concept and its definition by different stakeholders. The dimensions of independence as defined by interest groups and researchers will inform health care providers, policy makers and provide focus for an ongoing research trajectory that will aim to maximize independence for older adults and people with disabilities. Stakeholders' definitions of independence and shared decision making should inform the design of smart home technologies and dictate their terms and context of use.

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