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Towards Building Decision Support Tools for Older Adults at Home: A Qualitative Analysis

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Abstract. Older adults (and caregivers) face important health-related decisions which can have important consequences on their well-being, independence, and outcomes (e.g., where to live, how to stay safe, where to get care). There is a critical need for tools to help them make informed decisions that reflects what is most important to them. We report on a qualitative analysis of survey data collected from home care providers to inform the design and development of digital decision support tools for older adults.

Keywords. Digital decision support tools, Aging at home, Shared decision making

1. Introduction

An increasing number of older adults are aging at home where they often face important health-related decisions. Yet, many of them do not know where to access information and supports to help with making informed decisions. With our current system capacity pressures (e.g., lack of long-term care beds, shortage of health care providers, long wait-times) [1], digital decision support tools (DDST) can play a critical role to address information needs and inform decision making with care teams. There are few DDST to support older adult and health professional decision making outside of clinical settings.

In this study, we report on findings from a qualitative analysis of survey data collected from home care providers. Our findings are aimed at informing the design and development of DDST for older adults and their caregivers. This study is part of a broader program of research focusing on what older adults, caregivers, and interdisciplinary care team members need for shared decision making [2-5]. Shared decision making refers to a process whereby individuals and their care team make healthcare choices together [6]. Previous research identified older adults to be least likely to experience shared decision making [7]. In this study, we identify key information needs as part of a requirements gathering process to inform the design and development of DDST.

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2. Background

Older Canadians face many challenges including issues with accessing care, lack of health workers, and fragmented health information systems [8]. An estimated 1.8M unpaid caregivers (over 15 year of age) experience negative impacts on health and well-being, finances and family relationships [9]. There is an urgent need for DDST to support older adults (and their caregivers) at home. The Ottawa Shared Decision Making Framework (ODSF) is a well-established framework for assessing what individuals need for making informed decisions based on best evidence available and by what matters most to them [10]. To the best of our knowledge, this framework has not been applied to inform requirements gathering for digital tools.

3. Methods

3.1. Participants

A participant advisory group consisting of one older adult, one caregiver and two care providers, guided the research process. We conducted a web-based survey of home care providers who were recruited from a Canadian health care organization, SE Health. Participants were offered an opportunity to enter a draw for a $20 gift card.

3.2. Procedure

Participants were asked to assess how often they supported clients with making decisions, and to identify: 1) the most difficult decision for older adults to make, 2) their perceived level of involvement with shared decision making, 3) what they need to better support older adults in decision making, 4) how frequently they support older adults (and caregivers) with decision-making, and 5) who is involved in the decision making process. Ethics approval was obtained from the Université Laval, Quebec and Southlake Regional Health Centre, Ontario.

3.3. Data Analysis

We applied a directed content analysis approach to analyze de-identified textual data collected from a survey of home care providers [11]. The research question guiding our analyses was "to what extent does the Ottawa Decision Support Framework (ODSF) explain what older adults need to make the difficult decision of staying at home or moving?" Our previous study identified this decision as the most difficult for older adults to make [4]. Initial codes were based on the ODSF framework and adapted according to emergent data. Aspects that did not fit the categorization frame were used to create their own concepts based on inductive content analysis [11].

4. Results

We analyzed survey data collected from 120 home care providers pertaining to the decision of "whether to stay home or move" (20% of 614 surveys). Participants included

personal support workers (n=81), nurses (n=25), and others (n=14). Most participants were over 40 years of age (n = 90) and reported having over 5 years of home care experience (n = 77). Our findings offered supporting and extending evidence for the Ottawa Decision Support Framework (ODSF). Reporting incidence of codes that represented five main categories are detailed in Figure 1 below.

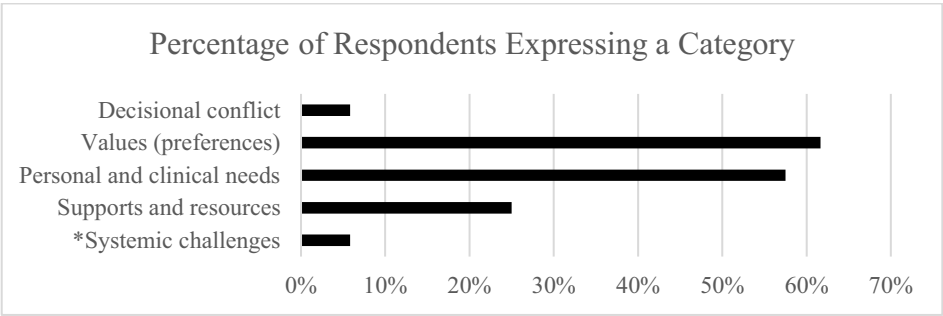

Figure 1. Incidence of five main categories (4 categories from the ODSF and *1 emergent category)

The concept of "Decisional Conflict" from the ODSF, referring to personal uncertainty about which course of action to take (e.g., wavering between choices, constantly thinking about decision),[12] was coded in 6% of the qualitative data collected from home care provider surveys. The "Values" category from the ODSF framework, referred to personal importance on options,[12] was the most frequently coded (62%). However, participants did not identify older adults to be "unclear" of their own values. Rather, their preferences (e.g., to stay at home) may conflict with their personal or clinical situation (e.g., safety concerns or need for support with activities for daily living), or their caregiver/family preferences (e.g., to move for safety, supportive care, or social activities). See Table 1 for sample quotes.

Table 1. Reporting incidence of values subcategories

Subcategory	**Sample quotes**	**Frequency**
Client preferences	*"Most of the elderly people whom I have spoken to preferred to stay at home by themselves if they still can and later require the help of a caregiver when they no longer able to do their ADLs. They are reluctant to go to nursing home."*	41%
Caregiver/family preferences	*"usually it is the children that would like their parents in a facility"*	18%
Cultural preferences	*"Certain cultures prefer to care for their older family members at home"*	1.7%

The "Personal and Clinical Needs" category of the ODSF framework, referring to "individual and health characteristic that can adversely affect decision quality and require decision support tailored to these special characteristics" [12], was the second most frequent category coded (58%). This category was rephrased as "situation" rather than "needs" to reflect participants' views on individual circumstances that may play a role in making the difficult decision. Expanding beyond the situation of older adults,

participants identified the situation of caregivers/family which can play a role in the decision-making process. See Table 2 below for sample quotes.

Table 2. Reporting incidence of sub-categories coded under Personal and Clinical Needs situation.

Sub-category	Sample quotes	Frequency
Client situation	*"This depends on a lot of options i.e. if they live with others, have caregivers, need social activity, personal capabilities, income to provide additional care assistance as needed, proximity to family/supports/activities"*	41%
Caregiver situation	*"[C]oncerns and fears feeling guilty about not being around stressed if something were to happen to there loved ones and should have could have!!"*	16%

The ODSF category "Inadequate Supports and Resources" offered a list of rich sub-categories.[12] Expanding on the concepts on "the assistance and assets needed to make and implement decisions" [12], sub-categories coded include opposing views (e.g., older adults vs caregivers, tension amongst caregivers/siblings, older adults vs health care authorities), pressure from others (family/caregivers, care providers), difficult decision roles (e.g., older adults unable to participate in decision making), information needs (e.g. facts on options). See Table 3 for sample quotes.

Table 3. Reporting incidence of sub-categories coded under supports and resources.

Sub-category	Sample quotes	Frequency
Opposing views	*"Family…has conflicts about where is best for family members, often siblings will have opposite opinions on this subject, one child…puts in more time and effort."*	7.5%
Pressure from others	"*Many are asked repeatedly by family if they will leave, or encouraged to leave...or even bullied into leaving"*	3%
Difficult decisional roles (ODSF)	*"Patient's family often make the decision which causes sadness."*	5%
Information needs	*"Caregivers suffer from guilt and lot of misunderstanding as to resour[c]es available"*	7%

5. Discussion

We identified several important considerations for designing and developing DDST for older adults and caregivers. Our study points to critical areas of DDST tool design, such as the need for tools to support information needs, and integration of data about activities of daily living to contextualize changes in personal and clinical situations of older adults (e.g., safety and clinical changes over time) and caregivers (e.g., caregiving burden and stress). Further, tools are needed to promote: informational support (e.g., options to stay safe at home), dialogue and collaboration, shared decision making (particularly for those who face pressure from family members and health professionals) to support difficult decisions regarding care and living at home when significant clinical changes occur (for the older adult) and caregiver burden rises.

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