# Emergency information management needs and practices of older adults: A descriptive study

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## ARTICLE INFO

## ABSTRACT

*Objective:* To better understand how older adults currently manage emergency information, the barriers and facilitators to planning and management of emergency information, as well as the potential role of information technology to facilitate emergency planning and management.

*Introduction:* Older adults face a much higher risk of sudden illness/injury and are the age group with the largest percentages of emergent and urgent healthcare visits. Emergency information (health information needed in an emergency situation such as emergency contact information, diagnoses, and advance directives) needs to be maintained and easily accessible to ensure older adults get appropriate care and treatment consistent with their wishes in emergency situations. Current health information technologies rarely take into consideration the emergency information needs of older adults, their caregivers, and emergency responders.

*Methods:* As part of a larger study we performed in-depth interviews with 90 older adults living in a variety of residential settings (independent living, retirement communities, assisted living) regarding how they manage information about their health. Interview sessions included photos of important health information artifacts. Interviews were transcribed and coded.

*Results:* Analysis of in-depth interviews revealed that emergency information is a type of health information that older adults frequently manage. Participants differed in whether they practice emergency planning (e.g. the preparation and continued management of emergency information), and in whether they involve others in emergency information and emergency planning. Despite its importance, emergency information was often not up-to-date and not always kept in locations readily apparent to emergency responders.

*Conclusion:* Emergency information, such as emergency contact information, diagnoses, and advance directives, is a type of health information that older adults manage. Considering emergency information in the design of health information technologies for older adults could address some of the barriers and support the facilitators to emergency planning and information management.

## 1. Introduction

Older adults face a much higher risk of sudden illness/injury and are the age group with the largest proportion of emergent and urgent healthcare visits [1–4]. Their vulnerability appears to be multifactorial but is often related to diminishing sensory inputs, cognitive dysfunction, disability, and impaired physiologic reserve. Given this vulnerability, the high prevalence of medical emergencies, and the reality that nearly one third of older adults live alone [5], it is essential to ensure that older adults are prepared, and have a way to communicate their

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particular health care needs, preferences, and expectations in the face of medical emergencies and potential disasters. These needs and expectations may include preferences about end-of-life care, resuscitation, emergency contacts, or power of attorney, as well as needs related to particular medical conditions, medications, and allergies. Information about health care needs, preferences, and expectations in an emergency situation that is gathered for use by emergency responders and others in the case of a medical emergency or disaster, will henceforth be referred to as "emergency information." The preparation and management of this emergency information will be referred to as "emergency planning."

There are a variety of approaches commonly undertaken by older adults in the US context to communicate emergency information to first responders. For example, advance care planning has been rising in the US; one study found that from 2000 to 2010, older adults who had advance directives in place increased from 47% to 72% [6].

One commonly used specific type of advance care planning used in the United States is the Physicians Orders for Life Sustaining Treatment (POLST) form, also known as MOLST in some states [7]. The POLST is a "standardized, portable, single-page, brightly colored and thus highly visible document, with the goal of translating a discussion between a patient and/or his/her surrogate decision-maker and physician into a medical order set that is legal across not just one care setting but across the continuity of possible care settings a patient may experience within a single state." The POLST form is intended for documenting preferences for end-of-life situations and there are programs to encourage or mandate use of this form in more than 40 US states [8,9]. However, it is unknown how many older adults complete POLST forms.

When emergency information is missing, a patient's preferences or needs may be unknown or misunderstood in an emergency situation. For example, in the United States, if resuscitation orders are missing or are not clearly communicated, first responders are required to attempt resuscitation [10]. Another challenge is that even when emergency information is present, paramedics don't always know how to interpret the materials and instructions provided [11]. Facilitating the management of and access to this information for family, friends and emergency responders through health information technology (HIT) could greatly assist in communication.

In the context of health informatics, it is imperative that we better understand the emergency planning and emergency information management needs and practices of older adults in order to design supportive systems for relaying up-to-date emergency information. In other words, it is necessary to understand how older adults are preparing, displaying, storing, updating, and sharing emergency information, and how we can help them overcome challenges to maintaining emergency information that is up-to-date and accessible. In the event that a medical emergency occurs and older adults are not able to convey their needs directly, accessible and accurate emergency information can reduce confusion and lead to better care [12,13].

Effective personal health information management (PHIM), through tracking and integrating one's own health-related information to support care decisions and actions, empowers people to actively engage in healthcare [14]. However, current health information technologies (HIT) that are designed to support PHIM, rarely take into consideration the specific needs of older adults [15]. Most prior work describes the PHIM needs and practices of other groups, such as families [16,17] or patients with acute or chronic conditions [18–22]. Of PHIM studies with older adults, most focus on needs for medication management [23,24] or improved usability [25,26]. Even though recent work calls for advancing HIT to better support the needs of older adults to share PHIM [27], emergency planning needs and practices of older adults have been largely unexplored.

In this paper, we describe the role of emergency information in older adults' PHIM that was uncovered through in-depth interviews as part of the larger SOARING project (Studying Older Adults & Researching Information Needs and Goals) [28]. The aims of the SOARING project (Soaringstudy.org) are: 1) to investigate the PHIM needs and practices of older adults; 2) to investigate the role of key stakeholders in older adult PHIM; 3) to develop a model of older adult PHIM; and 4) to develop a set of user-centered design guidelines for developing health information systems based on the needs and practices of older adults. Based on the broader findings from aim 1, this paper describes emergency information, emergency planning, and also offers suggestions for how emergency information could be incorporated into emerging HIT systems to ensure that this information is kept up-to-date and available for emergency responders, caregivers, and health care providers when needed most.

## 2. Material and methods

As part of the SOARING project, we conducted in-depth semi-structured interviews from May 2014 to September 2015, with 90 older adults living in different residential settings (assisted living, retirement community, and independent living). Participants were recruited by direct contact, through staff contacts at assisted living and retirement facilities, and with fliers placed at community centers. We used purposive sampling to recruit participants in diverse living situations as well as with diverse income levels, ethnic and racial backgrounds. For the purpose of the SOARING project, we defined older adults as individuals who were 60 years or older at the time of their initial interview.

Inclusion criteria for participation were: age of 60 years or older; residing in King County, WA; able to speak and read English; and demonstrating no significant cognitive impairment (as indicated by a score of 4 or higher on the Six-Item Screener) [29]. For inclusion in the emergency information analysis presented here, the participant had to mention emergency planning either in the affirmative or the negative (n = 84) during the in-depth interview. All procedures were approved by the University of Washington Institutional Review Board.

In-depth interview sessions lasted approximately 90–120 min and consisted of both structured and open-ended questions regarding general health status, health information, and personal health information management. Where possible, interviews took place in the participant's residence. Participants completed a series of validated instruments to measure burden of chronic disease [30], e-health literacy [31], social networks [32], and autonomy [33].

With participant permission, photos were taken of objects related to personal health information management. Photos were edited to remove personal identifying information. Two researchers (KO and JL) developed and applied a coding schema to all photos. Four photo codes were relevant to this manuscript: "contact information," "emergency alert system," "emergency information," and "end of life." Interview recordings were transcribed by a professional transcription service.

We used triangulation to ensure the trustworthiness of the qualitative data and minimize researcher bias [34,35]. We used a mix of researchers (two interviewers and three coders), subjects (older adults from a wide range of ages and demographic backgrounds), sites (various retirement communities, independent living situations, and assisted living facilities), and methods (in-depth interviews, longitudinal phone calls, and onsite artifact collection) for this study. This ensures that our findings are repeatable and transferable to other contexts, and reduced the likelihood of researcher bias. Three team members (KO, JJ, LL) reviewed a sample of six transcripts to develop an initial codebook. Transcripts were imported into an online qualitative analysis tool (Dedoose) [36]. Codes were developed by researchers through a grounded approach [37]. We conducted line by line coding of interview transcripts, field notes, and photos. Patterns and themes were drawn directly from the words and artifacts of subjects. Two team members (KO and JJ) applied the codes to interview transcripts and reviewed on a weekly basis. Over 10% of the transcripts were coded by both team members to check for inter-coder agreement. Inter-coder agreement was 90% across the double coded transcripts. The two researchers then