It's in the Fridge: The Practices of Older Adults in Managing Advanced Directives and Other Emergency Information

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ALTHOUGH there is a growing emphasis on the value of emergency planning through mechanisms such as advanced directives and standardized emergency forms, research has not examined how older adults gather and manage this information, or how they share this information within social support networks, retirement communities, EMS and clinical care systems. Research in this area would be particularly important for ensuring people's preferences are known to EMS at the end of their life. As part of our larger AHRQ funded SOARING (Studying Older Adults & Researching Information Needs & Goals) project, investigating the health information management practices of older adults, we explored the types and management of advanced directives and emergency information among older adults.

Methods: We conducted 60-90 minute in-depth interviews with 90 older adults (60 years and older). We recruited participants from retirement homes, senior centers and assisted living facilities. Participants were asked structured and open-ended questions about their needs and practices around managing personal health information. We recorded, transcribed, and coded interviews looking for themes using a Grounded Theory approach.

Results: Emergency planning materials were frequently mentioned by older adults in reference to managing personal health information. The most frequently occurring types of emergency planning materials included: advanced directives, medication lists, emergency contact information, and standardized POLST (Physician Orders for Life-Sustaining Treatment) forms. 71% (60 out of 84) of participants indicated that they have some type of emergency information in their place of residence. Of these people, 43% manage this emergency information independently, and 57% do so with varying levels of involvement from others, such as family, friends, and/or staff at a retirement community. Emergency planning materials were often initiated by retirement homes or assisted living facilities. Demographically, advanced planning increased with age (p=.05), and education level (p=.03). Many participants posted emergency planning materials in their living space; most commonly, this information was located on or in their refrigerator or on the back of the front door. A variety of reasons were given for why older adults don't have emergency planning materials. Many participants mentioned they simply don't keep emergency information updated. Some explained this was because they are currently healthy and do not anticipate emergencies. Other participants did not keep emergency information because such preparations make them feel "old". Others expressed uncertainty in their decisions regarding advanced directives.

Discussion: Emergency planning materials are an important aspect of health information management among older adults. Information systems designed to maintain health information should take into consideration the needs and practices of older adults to maintain advanced directives and other emergency information. Given that many of our participants managed emergency information collaboratively, an important function of these systems would be to allow older adults to update information easily as well as to grant viewing/editing capabilities to the person(s) of their choice. Because our participants primarily maintained emergency planning materials in a physical form, when designing digital systems, consideration must be given to how this information would be made available to first responders.

Conclusion: Our research indicates that use of emergency planning materials is an important, but understudied, activity of older adults. Taking into consideration the information management practices and needs of older adults, caregivers, emergency personnel, and other key stakeholders will be critical to designing clear and up-to-date emergency materials which meet the needs of older adults. Specifically, home care and hospice care providers will benefit from training that addresses how to acknowledge and integrate these information needs into the care plan. Furthermore, this information can be used to educate and support family members and other informal caregivers in their care of older adults.