



## How family members manage risk around functional decline: The autonomy management process in households facing dementia



Brandon Berry\*, Ester Carolina Apeso-Varano, Yarin Gomez

UC Davis, USA

### ARTICLE INFO

#### Article history:

Available online 13 February 2015

#### Keywords:

US  
Alzheimer's/dementia  
Symptom management  
Autonomy  
Functional decline  
Awareness  
Risk

### ABSTRACT

Most dementia research investigates the social context of declining ability through studies of decision-making around medical treatment and end-of-life care. This study seeks to fill an important gap in research about how family members manage the risks of functional decline at home. Drawing on three waves of in-depth interviewing in 2012–2014, it investigates how family members in US households manage decline in an affected individual's natural range of daily activities over time. The findings show that early on in the study period affected individuals were perceived to have awareness of their decline and routinely drew on family members for support. Support transformed when family members detected that the individual's deficit awareness had diminished, creating a corresponding increase in risk of self-harm around everyday activities. With a loss of confidence in the individual's ability to regulate his or her own activities to avoid these risks, family members employed unilateral practices to manage the individual's autonomy around his or her activity involvements. These practices typically involved various deceptions and ruses to discourage elders from engaging in activities perceived as potentially dangerous. The study concludes by discussing the implications that the social context of interpretive work around awareness and risk plays an important role in how families perceive an elder's functional ability and manage his or her activity involvements.

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In the US, seventy percent of the 5.4 million people who have Alzheimer's disease and related dementias are cared for at home (Alzheimer's Association, 2012). With the number of individuals who have dementia expected to grow significantly over the coming decades (Brookmeyer et al., 1998), household care likely will grow in proportion. Prior research has made progress in explaining important household consequences of the disease, including shifts in identities and interpersonal relationships (see Bunn et al., 2012). Yet there are still important gaps in understanding how dementia is reshaping the social order of millions of households. While research has highlighted the importance of autonomy and meaningful activity to the wellbeing of cognitively-declining elders (Everard et al., 2000; Moyle et al., 2011; Phinney et al., 2007; Popham and Orrell, 2012; Wenborn et al., 2013), it has not yet explained how family members manage functional decline in the elder's daily activities over time. This is an important gap in dementia research because 1) functional decline is associated with increased stress and burden for caregivers (Vitaliano et al., 2003) and 2) responses to dementia

by family members can influence long-term prognosis (Tschanz et al., 2013).

Research developing around the concepts of functional decline and the activities of daily life has not pursued a line of inquiry examining how householders interpret and influence the process over time. Rather, research around these concepts has sought different goals, including developing measures of decline and activity level and identifying psychological and neurological correlates of these measures. The current study frames functional decline as a social problem that householders interpret and attempt to manage in their everyday lives across the progression of the disease (see Beard and Fox, 2008 for a parallel social problems framing). It asks: how does a family deal with a member's gradual decline in activities that he or she had been competently performing for decades? How do they manage everyday household threats—including house fires, floodings, poisonings, car accidents, and financial escapades—that incompetence in daily activities may cause? Important theorizing in dementia research suggests the crucial role of social psychological factors in determining the level and expression of functional ability (Clare, 2002; Kitwood, 1997; Sabat, 2001). The current study expands on these ideas by

\* Corresponding author.

E-mail address: [brandon.berry@ucdmc.ucdavis.edu](mailto:brandon.berry@ucdmc.ucdavis.edu) (B. Berry).

showing how the social context of household care mediates individual expressions of functional decline.

Studies of social support around decision-making provide a useful foundation for a social process understanding of functional decline. This research examines how family members manage the affected individual's decisions around medical treatment, end-of-life care, finances, and moves to long-term care facilities (Davies and Nolan, 2003; Crisp et al., 2013; Menne et al., 2008; Samsi and Manthorpe, 2013; Wackerbarth, 2002). An important dimension of the work characterizes the level of involvement elders and caregivers have in the decision-making process and the effects that different levels of involvement have on caregivers and elders individually and on their relationship. Findings highlight the challenges families face in executing decisions that correspond with the authentic preferences of affected individuals, but do not explicate how management of the decision-making process relates to avoiding risks caused by waning functional ability more generally. Thus, this area of work examines social support around cognitive decline through a narrow strip of behavior that provides limited insight into the larger process occurring across the individual's natural range of activities.

A second, smaller collection of studies offer modest insights into the larger process, especially around familial attempts to help the individual maintain ability-based dimensions of personal and social identities. Linking identity to activity participation, a number of studies, for instance, tie the effort of promoting autonomy to the concern with preserving or protecting the individual's identity (Berry, 2014; Blum, 1991; Clare, 2002; Fontana and Smith, 1989; Perry and O'Connor, 2002; Phinney, 2006; Phinney et al., 2007). Perry and O'Connor (2002), for instance, describe how caregivers decrease the complexity of the elder's old activities so that they may still engage in them to some extent and preserve a sense of self identity. In complementary work, Clare (2002) identifies the coping strategies that family members and affected individuals collaboratively constructed in order to maintain normality and protect a sense of self. Relevant to the current study, she highlights how family members "struggled" to find the balance between constructively helping and "taking over in an undermining way" (143). Finally, the current piece also builds on work explaining how family members engage in "cognitive support work" in order to minimize confusion and disorientation in the elder's social interactions (Berry, 2014). This piece identifies the lay health practices that family members develop to minimize the effects of symptoms on everyday life. Whereas that work focuses on attempts to lessen confusion so that the individual can effectively maintain independent lines of conduct, the current piece focuses on attempts to manage involvement in everyday activities to lessen risk of injury to self and others.

While the literature offer insights into social support around ability decline, researchers still know little about how family members manage decline in an elder's natural range of daily activities—such as cooking, driving, shopping, and bathing—over time. Though researchers have developed numerous interventions designed to increase functional autonomy at home (see McLaren et al., 2013), there is little research elucidating how families navigate functional decline within the social context of their own households. This work advances the study of functional decline in dementia by revealing how family members become autonomy management practitioners who develop their own logics of support.

## 1. Methodology

### 1.1. Sample

This is a three-wave retrospective interview study with

individuals who provide caregiving to relatives diagnosed with Alzheimer's disease. In total, we conducted 45 interviews with 15 individuals over the course of 2 years (2012–2014). We recruited this non-probability sample through the Alzheimer's Disease Center at the University of California, Davis following IRB approval. Among these participants, 12 were adult-children and 3 were spouses of the affected individual. We utilized a pool of Latina caregivers assembled for a related project investigating the effects of social capital on dementia caregiving. When the study began, participants ranged in age from 44 to 77 and care recipients ranged in age from 67 to 96. Time since diagnosis ranged from 1 to 12 years with a mean of 3.73 years. Individuals with Alzheimer's disease about whom participants reported displayed varying degrees of disease advancement at the start of the study. Twelve of the fifteen participants lived with the individual with dementia part time (5 of 15) or full time (7 of 15). In these part time living arrangements, participants either stayed part of the week at the affected individual's home or switched off with a sibling in hosting the individual weekly.

### 1.2. Data collection

The findings were derived from data collected through three waves of in-depth, open-ended interviewing conducted over the course of 2 years. We interviewed participants three times each at six month intervals. In the first interview, we focused our questions on the period from the first signs of the disease until the moment of the interview. In the subsequent two interviews, we focused on the period since the last interview. Interviews typically lasted between an hour-and-a-half and two hours each. They were conducted by phone or in person and in Spanish or English depending on the participant's preferences. In total, 29 were conducted by phone and 16 were conducted in person. All interviews were digitally recorded and then transcribed verbatim. Each participant received a \$40 gift card for participating in each interview.

We began the interview process with the understanding that current research does not explain satisfactorily how families deal with the household risks that occur due to cognitive decline. We conducted interviews using an interview guide that we constructed before each wave of interviewing. We designed each interview guide to accomplish two main tasks: (1) to understand the nature of the participant's relationship to the affected individual over time and (2) to document the participant's concrete behaviors around the elder's daily activities over time. We accomplished the first task by asking questions about living arrangements, amount of time spent together, and the types of activities that they engaged in together. To complete the second task, we asked questions about the participant's perception of the affected individual's abilities in his or her common daily activities over time and about the participant's behaviors around the elder during these activity involvements. We asked participants to describe the step-by-step details of *how* specific events and situations had occurred in their households and discouraged participants from speaking in generalizations and abstractions (Becker, 1998).

Because trust is a crucial interpersonal achievement when seeking to gain insight into a stigmatized health condition like Alzheimer's, we made rapport-building a cornerstone of our research design. First, we used a multi-wave interview protocol to increase the likelihood of building trust and facilitating participant disclosure of emotionally-difficult occurrences (Weiss, 1994). Second, we selected an interviewer that shared a racial-ethnic background and language fluency with our participant sample and relied on her (Yarin Gomez, the third author) to conduct each interview.

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