



# Medication takeovers: Covert druggings and behavioral control in Alzheimer's



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## ABSTRACT

Older adults consume the most prescription medication in the U.S. For those who develop Alzheimer's disease, risk of medication misuse increases with the progression of the disease. Family members commonly intervene to lessen risks by taking over the management and administering of a medication regimen. Despite the potential for grave harm around the misuse of powerful drugs, few studies provide insight into the household social context of medication use for this disease. Drawing on 60 in-depth interviews conducted in four waves over 2.5 years, this study investigates how family members administered prescription and over-the-counter medications to elders with Alzheimer's. The findings detail how family members initially created and enacted the role of proxy-administrator to avoid self-administration errors and then expanded the role to manage disruptive behaviors. During this process, family members perceived themselves as working in partnership with doctors, especially in the effort to craft a regimen that controlled the affected individual's mood and sleep/wake cycle. The paper concludes by discussing the implications that family members used medications to improve conformity to a preferred household social order. The study offers conceptual advances in understanding 1) the process of proxy-administration in Alzheimer's care and 2) the role of proxy-administrators in the medicalization of deviant behavior.

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## 1. Background

Older adults are the largest prescription medication users in the US (Catlin et al., 2008). For the estimated 5.4 million who have Alzheimer's disease, maintaining a regimen grows more difficult as cognitive impairment progresses (Alzheimer's Association, 2012; Arlt et al., 2008). For the seventy-four percent living at home, most will rely on family members for managing and administering medications during the course of the disease (Alzheimer's Association, 2012). As communication difficulties grow, elders and their family members face an increasing challenge to use effectively powerful drugs that may cause discomfort or increase risk of death even when used as recommended (Schneider et al., 2005). Despite the heightened potential for harm, researchers know little about the social dynamics at play around at-home medication use in the Alzheimer's context.

Investigations into the social context of medication use for a

variety of health conditions over the last three decades provide an important foundation from which to examine the Alzheimer's case. These studies lay the groundwork for understanding how the meanings of a medication and the ongoing negotiation of the illness identity can lead to personally-meaningful use patterns that deviate from physician recommendations (see Conrad, 1985; Donovan and Blake, 1992; Karp, 1993). By highlighting social contextual dynamics around medication use, these studies offer a compelling alternative to narrow explanatory models identifying patient health beliefs or doctor/patient miscommunication as primary causes of "noncompliance" (Conrad, 1985; Dew et al., 2014; Donovan, 1995).

Though a highly productive turn in studies of medication use, this work almost exclusively examines one form of medication-taking: self-administration (see Pound et al., 2005). *Proxy-administration*,<sup>1</sup> or the practice in which one lay individual administers

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<sup>1</sup> This term is in limited usage in the health sciences literature related to, for instance, studies investigating whether parents can effectively manage a child's patient-controlled analgesia as a proxy in hospital settings (see Angheliescu et al., 2012).

medication to another, is widely practiced in cases in which the care recipient has a cognitively and/or physically debilitating condition, such as Alzheimer's, Parkinson's, traumatic brain injury, severe arthritis, vision loss, or in the parent/child context for conditions such as asthma, ADHD, and type one diabetes. Generally, the few studies that investigate proxy-administration do not examine the interpersonal dynamics influencing its at-home practice or its relevancy to theorizing in medical sociology (see Allotey et al., 2004; Carder, 2012).

An investigation of the at-home practices of proxy-administration advances an *interpersonal* rather than *institutional* understanding of medicalization. An interpersonal approach examines the role of individuals in applying a medical frame to understand or manage a problem that they are confronting personally. An institutional approach investigates the role of large-scale institutional actors in applying a medical frame to a problem (Conrad, 1992). Generally de-emphasizing the importance of interpersonal dynamics, the institutional approach commonly operates with a perspective critical of large-scale medical and pharmaceutical entities for engaging in profit-motivated disease-peddling. These studies typically focus their investigations on how problems become defined as essentially medical in nature through broad cultural, technological, and institutional shifts (see Scull, 1975). An institutional approach to Alzheimer's disease, for instance, details how senility became a problem because of the actions and interactions of institutional actors, including the National Institute on Aging and a group of career-driven neuroscientists (Fox, 1989).

An understanding of the institutional level of medicalization is indispensable for fully grasping the social origins of a medical condition, but a neglect of the interpersonal level can lead to a distorted model, especially around medication use. In a classic expression of this problem, for instance, researchers using an institutional angle employ the assumption that psychoactive medications invariably influence behavior toward passivity and acceptance of the status quo (Conrad, 1979; Blum and Stracuzzi, 2004; Koumjian, 1981). Offering critical appraisal of this framing, Timmermans and Berg (2003) rightly understand this approach to imply the inevitable control of medication users by the medication, or a kind of "technological determinism" (99). By neglecting the role of agency in how doctors and medication users interpret and manage a medication's effects, the institutional approach offers an essentialist treatment of medicalization.

In comparison, the interpersonal approach to medicalization is relatively undeveloped, but notably more agnostic about the political motives that may be contained within a medication. This approach to medication use explains how individual actors adapt, build, and/or employ a regimen to manage a problem they are facing (see North et al., 1995; Rogers et al., 1998). Fainzang's (2013) study illustrates recent advances in this area, detailing how lay individuals "self-medicalize" and subsequently treat themselves with pharmaceutical medications outside of physician supervision.<sup>2</sup> Her study raises the possibility that an individual can self-medicalize and self-medicate, and in so doing, reject ascendant medical discourse in favor of personal judgment and the advice of lay experts. Emphasizing the autonomy of the medication user, the author argues that medicalization and use of pharmaceuticals does not inevitably imply social control.

Complementing the interpersonal approach, a related literature connects social control and medication use in another way. This collection of studies shows how individuals in various capacities and acting through formal and informal channels try to exert

influence over a medication user's medication-taking to increase conformity to a doctor's recommended regimen. Formal means of exerting influence include, for instance, compulsory outpatient commitments (Scheid-Cook, 1993) and face-to-face pressures leveraged by doctors during consultations (Quirk et al., 2012). Informal means include the pressures exerted by the friends and family members on the would-be medication user (Francis and Patel, 2000).

Working from the interpersonal approach, a study of at-home proxy-administration opens up new conceptual terrain around medication use and social control. Researchers currently know little about how lay individuals, acting in the role of proxy-administrator, manage the regimen and administration of medications, some of which have behavior-altering effects. Drawing on four-waves of in-depth interviews, the current study offers a grounded, social process investigation of the role of proxy-administrator in the Alzheimer's context. Beyond the case of Alzheimer's, this investigation provides a basic conceptual foundation for further research into (1) the social context of proxy-administration for other health conditions and (2) the role of proxy-administration in interpersonal medicalization more broadly.

## 2. Data and methods

### 2.1. Participants

We designed a four-wave in-depth interview study over the course of 2.5 years with 15 individuals providing care to family members with Alzheimer's disease. We obtained IRB approval before recruiting a non-probability sample through the Alzheimer's Disease Center at University of California, Davis. Twelve participants were the adult-children of the elder with dementia and three were their spouses. All participants were of Latino descent. We made use of a sample of participants previously assembled for a study of how Latino families manage risk in Alzheimer's caregiving (Berry et al., 2015). At the start of the investigation, participant ages were between 44 and 77 and the ages of elders with dementia were between 67 and 96. Participants estimated time since diagnosis from 1 to 12 years with a mean of 3.73 at the study's outset. Participants reported sharing households with elders either part time (5 of 15) or full time (7 of 15). Three participants did not share a household with the elder. It is important to note that this study largely examines participants who lived with or partially lived with the elder. Findings may be different in studies of family members who do not live with the elder.

### 2.2. Data collection

We conducted 60 semi-structured, in-depth interviews with 15 participants over the course of 2.5 years. We interviewed participants four times each at approximately six month intervals. Interviews averaged two hours each and were conducted in person (21 total) or by phone (39 total) and in English or Spanish. The in-person interviews were conducted in a university medical center office without the presence of the person with Alzheimer's. Participants received a \$40 gift card after each interview.

Our overarching interview strategy involved eliciting reports of all medication-related activities and social interactions between family members and elders since the first signs of the disease. We designed these questions as a conscientious attempt to understand the family member's experiences of medication-giving. For the first interview, our questions focused on the period of time from the first signs of the disease until that interview. In the next three interviews, our questions mainly targeted the period since the last interview. We developed a general interview guide for the first

<sup>2</sup> The authors thank Peter Conrad for providing this reference in a private correspondence.

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