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Trina Stolp
Boise State University

Mary Brown
Boise State University

Sarah Toevs
Boise State University

Mike Berlin
Boise State University

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Prepared by Center for the Study of Aging
Boise State University

Trina Stolp
Mary Brown
Dr. Sarah Toevs
Mike Berlin

BOISE STATE UNIVERSITY
CENTER FOR THE STUDY OF AGING

Executive Summary

Enhancing quality of life for people with dementia is identified in Healthy People 2020 as a public health priority. In Idaho, the proportion of individuals diagnosed with Alzheimer's disease and related dementias (ADRD) is projected to increase by 81 % - 127 % between 2000 and 2025. Policies designed to address needs of this population must be based on an understanding of system wide impacts of disease. The purpose of this exploratory study was to examine the impact of behavioral crises related to dementia on first responders. For the purpose of this study, "first responders" were defined as individuals employed by the Idaho Department of Health and Welfare Mobile Crisis Unit in Regions 1, 3, and 4, Ada County Paramedics/EMS, and social workers employed in health care settings in the Treasure Valley.   A mixed methods design was used with information gathered from incident reports from the Ada County Paramedics and focus groups and interviews with key informants.

Ada County Paramedics/EMS receives approximately 22,000 calls annually with 924 of calls related to behavioral crisis involving individuals with ADRD. Most calls were from assisted living facilities (n=401), home (n=290), or skilled nursing facilities (n=181).   The majority (80%) of calls resulted in transport to a hospital emergency department (ED); none of the calls required use of lights or siren. Annual costs of calls to EMS and ED were estimated to be $457,380 and $905,020, respectively.

Themes from key informants included: an increase in number and complexity of calls; lack of appropriate protocols within systems to support individual in crisis or their family or caregiver; and need for training on progression of ADRD and de-escalation strategies.

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Background

Estimates provided by the World Health Organization document 35.6 million people living with dementia in 2010 and predict the doubling of this number every 20 years (Tam-Tham, Cepoiu-Martin, Ronksley, Maxwell, & Hemmelgarn, 2013). The management of aggressive behavior, both physical and verbal, expressed by individuals with dementia poses a significant challenge for families, first responders, and health care systems. Aggressive behaviors can escalate to a crisis and cause great distress for all involved in the incident. In many situations, the only avenue available to families and caregivers is to call 9-1-1 or other first responder systems.

The purpose of this exploratory study was to examine the impact of behavioral crises related to dementia on first responders. For the purpose of this study, “first responders” were defined as individuals employed by the Idaho Department of Health and Welfare Mobile Crisis Unit in Regions 1, 3, and 4, Ada County Paramedics/EMS, and social workers employed in health care settings in the Treasure Valley.

Literature Review

The Healthy People 2020 report published by the Center for Disease Control and Prevention identifies two goals specific to dementia; 1) reduce costs associated with the disease and 2) maintain or enhance the quality of life for people with dementia (Office of Disease Prevention and Health Promotion, 2014). Objectives related to these goals include early detection of the condition and reduction of preventable hospitalizations (Office of Disease Prevention and Health Promotion, 2014).

Reporting of Dementia

A review of the literature revealed that documentation from hospital emergency department (ED) records of encounters involving individuals with dementia in behavioral crisis may not adequately describe the frequency of these events (Hustey & Meldon, 2002; Fillit, Geldmacher, Welter, Maslow, & Fraser, 2002; Valeriani, 2011). Fillit et al., (2002) identified that dementia and associated conditions were “grossly under-coded” in the acute care and outpatient care setting due to failure to diagnose, limitations of the coding system, and lack of reimbursement for dementia related care. For example, there is only one ICD-9 code related to for dementia related conditions (Fillit et al., 2002). Finally, there is no billable code related to the admission of an individual in behavioral crises associated with dementia. This lack of ability to bill for charges can lead to “up-coding” of an encounter to a secondary, but billable diagnosis, such as dehydration, urinary tract infection, or schizoaffective disorder (Valeriani, 2011). These documentation challenges distort information describing patterns of use and costs and also impact the quality of care and support provided to the patient and families (Fillit et al., 2002).

Cost of Care

A report published by the National Institute of Health (NIH) in 2015 revealed that healthcare spending for an individual with dementia was 57% higher than any other disease over the last five years (National Institutes of Health, 2015). Based on findings from NIH, out-of-pocket costs for informal and formal care for an individual with dementia were almost double when compared to costs of providing care for someone without dementia. For example, expenditures for *formal* care for dementia were $61,522 versus $34,068; *informal* care costs were $83,022 versus $38,272 (National Institutes of Health, 2015).

The costs to families providing support to individuals with dementia have also increased. In 2010, it was estimated that caregivers provided 1.3 billion hours of assistance each month, with 532 million of these hours invested in caring for individuals with dementia at an estimated value of $159-215 billion (Kasper, Freedman, Spillman, & Wolff, 2015). Because of the time and case management required to care for an individual with dementia, caregivers need support and resources. Without these resources, the capacity of caregivers to delay the institutionalization of a family member with dementia is significantly diminished (Tam-Tham, Cepoiu-Martin, Ronksley, Maxwell, & Hemmelgarn, 2013). Many family caregivers also sacrifice potential income due to the nature of the disease and unlike other terminal diseases, the progression of dementia can span years and progress to requiring 24-hour care and crisis management due to the instability and volatility of the individual.

Methods

The purpose of this exploratory study was to examine the impact of behavioral crises associated with dementia on first responder systems and families. A mixed methods design was used with information gathered from incident reports from the Ada County Paramedics and focus groups and interviews with key informants. All research procedures were approved by the Boise State University Institutional Review Board.

Incident Records

Incident records for calls involving individuals with a diagnosis of dementia during 2013 and 2014 were provided by the Ada County Paramedics. The records included information about date of incident, age, primary impression, past medical history, location of call (e.g. home, nursing home, street), location name, disposition, destination transported to, and total call time.

Key Informant Questionnaire

A questionnaire, developed by the researchers and pilot tested with professionals with expertise in crisis intervention and dementia, was used to guide focus group and interview discussions. The questionnaire gathered information about the frequency and location of calls, amount of time required to deescalate a behavioral crisis, typical patterns of resolution of incidents, and the needs of family caregivers and first responders when addressing a crisis.

Focus Group Participants

Participants for the focus group were recruited from social workers employed with the Idaho Department of Health and Welfare Mobile Crises Units from Region 4. The invitation to participate in the focus group included a copy of the questionnaire and informed consent document. Ten social workers participated in the focus group conducted on September 23, 2015. The discussion was facilitated by the primary researcher, an academic advisor, and audiotaped and transcribed by a research assistant.

Interview Participants

Individual interviews facilitated by the primary researcher using the key informant questionnaire were conducted between October-December 2015. Participants included two social workers from the Idaho Department of Health and Welfare Mobile Crisis Unit from Region 1 and 3, two social workers employed by a health care system, and an attorney with experience as a county prosecutor with oversight for involuntary mental hold proceedings. All the interviews were conducted in a private setting and transcribed for analysis.

Analysis

Quantitative and qualitative methods were used in the analysis of findings. Descriptive statistics were used to explore and summarize the information provided in the incident records. Information from the focus group and interviews was coded and analyzed by the research team to identify response patterns and themes.

Results

Incidence Records from Paramedics/EMS

Analysis of incidence records from 2013 and 2014 revealed that approximately 22,000 calls were received from emergency dispatch each year. Of those calls, about 900 per year were related to behavioral crisis involving an individual with dementia. The average age of the individual with dementia was 84 (range: 38-103). The most common settings generating the calls were assisted living facilities (n=401), the individual's home (n=290), and skilled nursing facilities (n=181). The most frequent primary impression was traumatic injuries (n=314). See Table 1 for additional details about calls to EMS for individuals with an identified primary diagnosis of dementia.

Table 1 Calls to EMS for individuals identified primary medical history of dementia

Age (Mean and Range), Setting and Primary Impression		
	2013 n=890	2014 n=924
Age Mean	84.31	83.82
Age Range	38-102	50-103
Settings of EMS Calls	%(# of Calls)	%(# of Calls)
Assisted Living Center/Rehabilitation Center	43.1 (384)	43.4 (401)
Home	31.8 (283)	31.4 (290)
Nursing Home/Residential Center	18.6 (166)	20 (181)
Other Specified Places (i.e. Businesses, Street)	4.7 (42)	4.1 (38)
Hospital/Doctor's Office	1.7 (15)	1.5 (14)
Primary Impression		
Traumatic Injury	35.3 (314)	31.6 (292)
Neuromuscular/Generalized Weakness	13.1 (117)	11.9 (110)
Pain	12.1 (108)	13 (120)
Altered Level of Consciousness	12 (107)	14.9 (138)
Respiratory	5.4 (48)	4.9 (45)
No Complaints or Injury/Illness Noted	5.1 (45)	3.5 (32)
Behavioral/Psychiatric Disorder	4.8 (43)	3.9 (36)
Hemorrhage Complaint	2.4 (21)	1.6 (15)
Fever/Infection	2 (18)	2.5 (23)
Cerebrovascular Complaint	1.8 (16)	2.8 (26)
Diabetic Complaint	1.7 (15)	1.3 (12)
Cardiovascular Compliant	1.6 (14)	2.8 (26)
Gastrointestinal Complaint	1 (9)	2.3 (21)
Seizure	.8 (7)	1.2 (11)
Other Complaints	.8 (7)	1.7 (16)
Unknown (Missing)	.11 (1)	.10 (1)

The average length of time required for emergency calls involving an individual with dementia was 45 minutes. The majority (80%) of the calls resulted in the transport to a hospital emergency department (ED) although none required the use of lights or siren. The average cost of these calls to the paramedics/EMS system was approximately $450,000 per year excluding agency readiness costs. See Table 2 for additional information.

Table 2 Average Length, Disposition, and Cost of Calls Involving Individuals with Dementia

Average Length, Disposition, and Cost of EMS Call for Individuals with Dementia		
	2013 n=890	2014 n=924
Average (range) Minutes on EMS Call	45.14 (13-118)	46.55 (12-126)
Disposition	% (# of Calls)	% (# of Calls)
Transported No Lights/Siren	79.6 (708)	74.8 (740)
Emergency Department	94.2 (667)	94.9 (702)
VA	5.8 (41)	5.1 (38)
No treatment, No Transport	16.4 (146)	16.6 (153)
Treatment at Call Site, No Transport	4.0 (36)	3.6 (31)
Cost of EMS Calls Related to Dementia @ $495 per call (not including agency readiness costs)	$445,000	$462,000

Focus Group and Interviews with Members of Mobile Crisis Unit

Responses from the focus group (n=10) and interviews of social workers (n=2) from Idaho Department of Health and Welfare Mobile Crisis Units in regions 1, 3, and 4 identified the need for more resources, specifically education, training, monetary support for the caregiver and facilities equipped to manage dementia-related behavioral crises. Respondents from all settings and regions of the state indicated that the number and complexity of calls had increased with more calls coming from individuals with dementia, family members, and caregivers looking for resources and education regarding the disease. Common questions from callers were related to:

- strategies that could be used to de-escalate a behavioral crisis,
- guardianships, and
- information about placement in long-term care facilities.

The average length of time for conversations related to these calls was 30 minutes. However, if the call required the social worker to conduct fieldwork, i.e., go to a medical facility, the call could require 6-12 hours to achieve resolution. One respondent said,

> “Generally if we get this type of case, it’s a lot more time consuming, because there isn’t a system set up to handle the situation. … there isn’t anywhere for them to go, and they can’t go back with their family because of the behaviors, and so you end up spending much more time trying to figure out the situation.”

Hospital Social Workers

Information gathered from emergency department and inpatient social workers (n=2) revealed on average, approximately 4-5 patients experiencing a behavioral crisis related to dementia at any given time. Respondents reported an increase in the frequency of patients in crisis seen in the emergency department (ED) and inpatient census.

The average length of ED observation for an individual with dementia experiencing a behavioral crisis was estimated to be 6-8 hours with the individual being transferred to inpatient status if not be stabilized. During inpatient status, social workers typically assist families and caregivers with discharge planning to long-term care facilities. However, this often requires the establishment of guardianship which many families/caregivers do not have in place. This can delay placement and result in an individual remaining in an inpatient setting for an extended period of time.

The respondents also expressed concerns about treating individuals with dementia in a hospital setting because of the lack of experienced geriatric therapists and therapeutic environment, (e.g. quiet and familiar). One respondent shared,

> "… This [inpatient setting] is not the environment for them, so the patient themselves, is not getting what's best. We don't have the set-up. We don't have a rec room, we don't have activities, we don't have the recreational therapy staff person who's going to take them outside for a walk."

They felt these and other factors often lead to increased agitation for the individual in crisis, resulting in longer hospital stays due to patient's inability to be stabilized for discharge.

The respondents also identified a lack of caregiver capacity as a primary reason for events escalating to a crisis situation. Often the individuals tasked with providing the day-to-day care do not have appropriate memory-care training, are not equipped to prevent or de-escalate a crisis, and do not have the social support needed to manage the physical and mental strain of providing care. The severity of mental fatigue burdening families and caregivers is further exacerbated by the lack of available respite services. Respondents also highlighted the need for education and resources for family and specialized facilities equipped to address dementia-related behavioral crises.

Former Prosecuting Attorney

The interview with the prosecuting attorney provided additional insight on barriers experienced by individuals with a history of dementia. Based on his interpretation of Idaho law, an individual in behavioral crisis related to dementia cannot be for placed on an involuntary mental hold because dementia does not fall within the statutory definition of a mental illness. Current statutes classify dementia as a medical condition rather than a mental illness, which prevents the use of an involuntary mental hold when for an individual with dementia is experiencing a behavioral crisis.

Currently the only way the police can detain an individual with dementia is to determine they are of danger to themselves or others and charge them with a crime. A charge of this nature typically results in an individual being detained in a municipal jail or other correctional facility and held until a competency evaluation can be completed. The trauma of the incarceration process often leads to an increase in unmanageable behaviors, and the required legal process to determine competency is costly. The interviewee also stated that the outcomes of the competency hearings are generally a ruling of "incompetence" at a significant cost to the taxpayer, as well as time and resources of the Judicial System, prosecuting attorneys, and Idaho Department of Health and Welfare.

Discussion

The purpose of this study was to examine the impact of behavioral crises associated with dementia on first responder systems and identify opportunities to enhance existing supports, policies, and systems. Recommendations in the areas of information and education, caregiver respite, and policy, and systems emerged from the findings.

Information and Education

Due to the progressive nature of dementia, the need to provide family and caregivers with the "right" educational resources at the "right" time was identified by many key informants. Several respondents suggested that individuals and families "at risk" and in need of information could be identified through the use of call records from police, EMS, and mobile crisis systems. Information and education was identified as critical to reducing the frequency of contact with first responder systems. For example, providing caregivers with information about how to use "redirection" techniques can reduce combative responses from the individual with dementia. By helping the caregiver understand what is normal versus abnormal, they will be better able to identify changes in behavior and take action to deescalate a potential crisis. Caregivers also need information about when and how to transition a family member to a higher level of care such as assisted living or skilled nursing. Empowering families and caregivers with information about dementia and the behaviors to anticipate will also lead to improved communication skills between the individual with dementia and their caregivers and family.

Caregiver Respite

All first responders agreed the caregiver or family member has an overwhelming task to provide care for individuals with dementia. First responders identified the need for respite and felt these services were key to preventing the mental and physical fatigue experienced by caregivers. In addition, the first responders indicated that family members and caregivers would need assistance in navigating the array of funding options and respite resources available in their communities.

Policy and System Change

Several common policy and system-related recommendations emerged from key informants. These included the need to:

- increase access to facilities equipped to stabilize and manage behavioral crisis situations,
- establish a mental hold-type option for individuals in crisis to assure safety and a comprehensive assessment, and
- streamline the guardianship process with the goals of saving time and money and improving the quality of life for individuals with dementia and their caregivers.

According to all respondents, solutions must include access to facilities or units within existing facilities that are equipped to manage behavioral crises related to dementia. These services are available in surrounding states, but are very limited or nonexistent in Idaho.

Key informants also identified the need to review policies involving mental holds. In Idaho a mental hold applies only to mental health conditions and *not* medical conditions. Because dementia is classified as a medical condition, the protections a mental hold affords do not apply to individuals in crisis due to dementia. The inability to temporarily restrain or detain an individual exhibiting behavior that could be of danger to themselves or others puts the public at risk. It can also lead to potential “up-coding” of a patient’s condition to facilitate the placement of a hold or to a condition that is billable. As noted by Fillit and colleagues (2002) and Valeriani (2011) this leads to distortion of data used to track utilization of health care services by individuals experiencing a behavioral crisis related to dementia.

Finally, respondents identified significant gaps in policies and processes related to guardianship. For example, it was reported that establishing a guardianship can cost $2,000-$3,000, but if it is contested, costs can be upwards of $10,000. These expenditures can put significant financial pressure on a family or caregiver and a protracted process can lead to much longer hospital stays than medically necessary.

The goal of this exploratory study was to describe the impact of behavioral crises related to dementia on first responders in Idaho. Limitations of this study include the geographic distribution of key informants and reliance on information from secondary sources to describe the impact of behavioral crises on caregivers and families. Interviews with individuals with dementia and their families and caregivers and personnel from health care systems (hospitals), long-term care facilities, and Veteran's Administration throughout Idaho would be beneficial.

Conclusion

The number of individuals being diagnosed with dementia will continue to increase over the next 20 years. It is imperative we recognize the human and financial costs to individuals and systems of not effectively addressing behavioral crises related to dementia. Taking heed of recommendations provided by first responders, those on the front-line of behavioral crisis situations, in this report will benefit individuals and the State of Idaho. Providing education and respite care will decrease the number of calls to first responders. Assuring access to facilities equipped to deescalate and stabilize individuals experiencing a crisis will achieve more effective outcomes. And, finally updating policies and statutes related to mental holds and guardianships will enhance public safety and help ensure the efficient use of public and private resources.

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