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National Priorities for Dementia Care:

Perspectives of Persons Living with Dementia and their Care Partners

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National Priorities for Dementia Care:**Perspectives of Persons Living with Dementia and their Care Partners****Abstract**

Purpose: To report on the consensus recommendations from people living with dementia and their care partners on priorities for public policy and research funding.

Design & Methods: A nationwide, Delphi study among persons living with dementia and their care partners. A modified snowball sample was used. Listservs, personal contacts, and advocacy groups were asked to distribute the survey. Paper versions were provided upon request.

Results & Implications: Round one: 388 responses were received. Round two: 301 were received. Borda counts produced a ranked order consensus of priorities. Research ranked third, after the need for caregiver support and resources for the provision of long-term care. Education and training in particularly person-centered practices for all care partners was also a high priority. Responses indicated that research funding should be expanded beyond its current emphasis on cure. Policymakers should reconsider the current priorities of NAPA in order to better address the long term needs of people living with dementia and their care partners.

5 **Keywords**—Dementia, NAPA, Alzheimer's, Person-Centered Care, Delphi

National Priorities for Dementia Care:

Perspectives of Persons Living with Dementia and their Care Partners

Introduction

In 2011, the National Alzheimer's Project Act (NAPA) was signed into law. A key provision of NAPA required the creation of an Advisory Council comprised of federal and non-federal representatives involved in aging issues. One of the tasks set by the Advisory Council involved the development of recommended priorities needed to prepare the U.S. to meet the needs surrounding Alzheimer's disease and related dementias (Department of Health and Human Services, 2014). While most of the five goals forming the National Plan are oriented on aspects of care [e.g., quality of care, access to needed supports and services, advocacy and public education], the majority of the plan's emphasis and resources are directed to cure and treatment. In 2014, over \$100 million was allocated to science and drug development and \$10 million to care, services and education (Department of Health and Human Services, 2014). The Alzheimer's Association estimates that over 5 million people have Alzheimer's Disease; this represents less than \$2 per person for care related support from NAPA. It is critical to find cures and medicines for Alzheimer's and related dementias. However, are these the priorities that people and families living with dementia want? Their voices have not been heard over the clamor for research dollars to cure Alzheimer's.

This study was part of a larger project to develop a national advocacy group, the Dementia Action Alliance, providing an opportunity for people living with any type of dementia and their care partners to contribute to the national debate and the National Plan. The study sought to obtain a consensus of recommendations from people living with dementia and their

care partners on priorities for public policy and where research funded by public dollars should be directed. The data in the study was presented as a public comment at the NAPA council meeting in July 2014.

Methods

A two-round Delphi technique was used to gain consensus from a geographically spread panel of people living with dementia, their care partners, and supporters. The Delphi technique offers a number of advantages, including the ability to: obtain geographically spread experts; avoid the dominance of any one voice or group; and have multiple rounds, allowing participants to view other opinions. The method was first devised by the Rand Corporation in the 1950s to garner opinions of experts to forecast technological developments in military and marketing (Fink, Kosecoff, Chassin, & Brook, 1984; RAND Corporation, 2015). In health sciences it has been adapted to gain consensus amongst experts around priorities for research and education (Jones & Hunter, 1995; Keeney, Hassan & McKenna, 2006; Tolson, Maclaren, Kiely & Lowndes, 2005; Walker & Selfe, 1996). Although the method has been used predominantly with professionals who are specialists in their subject matter, in this study we recognized that the people living with dementia and their supporters were the experts in this experience.

Sample

A modified snowball sampling strategy was used. Two distinct groups with important perspectives and knowledge about person-centered dementia care were the primary contacts for disseminating the online survey: (1) two grassroots dementia advocacy groups; and (2) 27 national organizations that advocate for people living with dementia and their care partners. These groups were asked to disseminate the survey to their members and networks. In addition, email networks from the project team, listservs, and personal contacts were used to distribute the

SurveyMonkey® link to as many people living with dementia and their care partners as possible. The same organizations, contacts and networks were used for round two. Questionnaires were also mailed with postage-paid return envelopes and one participant telephoned to give his response. Responses were entered into SurveyMonkey® by SS. In round one, 388 people participated and in round two 301 people participated. Participants had a diagnosis of dementia (including Alzheimer's) or were supporting an individual living with dementia.

Approval to conduct the study was obtained from the University at Buffalo (UB) Institutional Review Board for Social and Behavioral Sciences. Consent to participate was included on the initial screen of the SurveyMonkey® link. No identifying information was gathered.

Analysis

We undertook two rounds for this Delphi using a survey available online or on paper. In round one, participants were asked to state what they perceived as the needs of people living with dementia and their supporters and to identify priorities for government policy and publicly funded research. A simple content analysis was conducted, and responses were grouped into thematic areas for potential priorities.

In round two, participants were asked to rank the identified topics that emerged in terms of importance. This round resulted in a more complex task of responding to 11 topic areas in two major groupings: priorities for government and priorities for research. Each grouping began by ranking the categories followed by ranking of topics within categories.

For round two, calculation of consensus ranking was performed using a voting system referred to as a Borda count, a single-winner election method in which voters rank options in order of preference (Saari, 2008). The Borda count determines the outcome by giving each

candidate points corresponding to the number of candidates ranked lower. Once all votes have been counted the candidate with the least points is the winner. This may seem counter intuitive but ranking the top option as 1 (or first) and the least favored option as 5 (or fifth) results in the lower numbers representing the highest preference.

Demographics from each round are shown in Table 1. Table 2 reports what relationships the respondent had/has with a person living with dementia. To overcome response problems from SurveyMonkey® we used the following rules for reporting. Please note we used number of "responses" rather than number of "participants" as the denominator.

Results

The analysis from round one provided a wealth of ideas and revealed the burdens, both emotional and financial, which beset the participants. We focused the analysis on two questions that specifically asked participants for Federal Government priorities and Research priorities in order to create the items for the round two ranking. The results provided 11 sets of statements for ranking. Each set had between three and six statements; the majority had five.

After calculating the Borda count for each set, we produced a ranked order of preference for prioritizing each topic area based on the consensus views of participants. The following tables detail the Borda count and the final ranking (Tables 3 and 4). After each set of rankings, participants were given the opportunity to comment. Common to all of the comments was the difficulty for participants in choosing between the statements.

The results appear in the order presented in the survey. The first section of each table indicates the ranking of each priority area, including research, providing the overall importance

of each issue. This is followed by the detailed rankings within each issue with the government priorities first then the research priorities.

This study's findings indicate that research is important to people living with dementia and their supporters. However, research (both cure- and care-related) is ranked third, after the need for support for caregivers and resources providing long term care. If the national plan followed the order of priorities identified in this survey, funding would be allocated as:

1. Financial and other resources to support caregiving
2. Financial and other resources to support long-term care and aging in place
3. Research for cure and care
4. Person-centered education and training for families, health professionals, nursing aides, and volunteers
5. Advocacy and awareness to reduce the stigma of dementia

For the research agenda, priorities would be more diverse including a multitude of care issues that were raised. Most people want a cure or a means of preventing dementia to be found. The reality of this happening by the 2025 deadline was not supported. As one participant wrote:

“I have known for a long time that there will be no cures in my lifetime. Maybe in my children's, not sure now, not even sure if in my grandchildren's. So there has to be some more emphasis/support/help for caregivers, and some way has to be found to pay for care- in home. Facilities in my area are costing \$10,000 per month. No way is this affordable.”

The specific priority areas for research were as follows:

1. Cure, prevention and treatment.

2. Caregiving including person-centered care, family caregivers, and workforce issues
3. Education and training including for the person with dementia, families, workforce, and the public
4. Quality of life including the impact of dementia on the whole family
5. Complementary therapies including supplements, remedies, and alternative treatments
6. Care settings and environments including the home, long-term care facilities, day care, and hospitals.

Discussion

This study sought to obtain consensus on issues related to dementia from the people most affected- people living with dementia, their care partners, and supporters. Dementia, including Alzheimer's, is a complex, chronic condition which impacts every aspect of life. The biomedical approach, which views dementia as neurodegenerative pathology alone, has been rejected worldwide by dementia advocates (Batsch & Mittelman, 2012; Prince, Guerchet, & Prina, 2013). The person-centered approach to healthcare recognizes that health and well-being are contingent upon more than the physical condition and include the psycho-social-spiritual dimensions (Kohn, Corrigan, & Donaldson, 2001). The need to recognize the entire impact on the individuals as well as the impact of caregiving for family members, professionals, and their communities has also been highlighted worldwide (Wortmann, 2013; Batsch & Mittelman, 2012; Prince, Guerchet, & Prina, 2013). Significant policy documents have highlighted the necessity of taking a person-centered approach, but this is not reflected in the National Plan (Kohn, Corrigan, & Donaldson, 2001; Wortmann, 2013). Indeed dementia care experts across the country are concerned about the current direction of the National Plan, specifically: (1) language too narrowly focused on Alzheimer's disease and not more globally on dementia; (2) too much

emphasis on the “cure” and too little on the “care” for people living with dementia; and (3) the Plan’s silence on what is considered the gold standard, person-centered practices (National Dementia Initiatives, 2014).

Person-centered approaches to care, including how to educate and train both professional and family caregivers on these approaches was a need made clear throughout the responses. Putting the person and family living with dementia at the center of all care practices, policy and research was a repetitive theme. Thus, findings suggest that current federal priorities be reexamined in order to provide for and adequately address the care needs of individuals living with dementia and their care partners.

Participants were also clear that not all research funding should be focused on cure. That so many research ideas were generated indicates the scope of work needed to produce a strong evidence base for practice/services. Without rigorous research, the ability to develop effective interventions on community, regional, state or even national levels is nearly impossible.

Limitations

Ideally the study would have happened over a longer period, making possible a third round to increase clarity of priorities and add participants particularly those living with dementia. The electronic communication and online form may have limited participation. However, little evidence exists on how best to engage people with dementia in research. Alternatives for engaging primary stakeholders must be considered for future research. However, adhering to this timeframe and communication format made it possible to present the findings at the NAPA council meeting in July 2014. Despite the limitations, we succeeded in engaging people living with dementia, care partners, and direct caregivers from over thirty U.S. states. We obtained over 300 participants in each Delphi round with over 90% of those completing part of the survey.

Implications for Nursing Practice

The needs of people living with dementia and their care partners are great. Our findings were supported by the parallel study by the RAND Corporation (Shih, Concannon, Liu, & Friedman, 2014) that, despite very limited engagement with people living with dementia, found the same results. In addition to all the ideas generated by this survey, there was a clear call for action.

Nurses and other health professionals are well positioned to take action as individuals on a daily basis and as a professional group in order to initiate many of these priorities. They are among the first to come in contact with individuals and families living with dementia who are in need of resources and support. Advocacy and education regarding the need for greater consideration of the priorities of persons with dementia rest squarely within our profession, and are essential to improving the quality of life for individuals and families. Person-centered practice considers the whole person and family, keeping their interests, values, relationships, and aspirations at the center of life and care. Currently, care is organized more around the convenience of the system or organization rather than the person receiving it. As the Eden Alternative Principle 7 states: Medicine should be the servant of genuine human caring, never its master (Eden Alternative, 2012).

For nurses and all health professionals, specialist skills are essential to sustain personhood through interaction and purposeful activity as this helps to retain meaning in life. It is not just about being nice. Person-centered practice requires a complex communication skill set delivered with empathy and creativity. McCormack and McCance's theory on Person-Centered Nursing provides a framework for promoting these high-level interpersonal and organizational competencies (McCormack & McCance, 2010). By role modeling these behaviors, health

professionals can lower stress for the person and family living with dementia while promoting awareness and reducing stigma more generally. As indicated in this study, staff and family education and practice development are critical to achieving these goals. Whether the person living with dementia is at home or in a long-term community living setting, placing the individual at the center of care provides a way to meet all their needs and goals on a daily basis. Utilizing this approach also has the potential to lower long-term care costs because individuals and families are equipped with the resources needed to support aging in place.

Conclusion

Currently, the vast majority of federal resources are dedicated to finding cures and treatments for Alzheimer's disease. While these are important objectives, results of this study align with previous research indicating that person-centered dementia care is an even higher priority. Findings suggest that policymakers reconsider the current priorities of NAPA to better address the long term care service and support needs of people living with dementia and their care partners.

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