Engaging Multi-Stakeholder Perspectives to Identify Dementia Care Research Priorities

For which topic were research priorities identified?
dementia

In which location was the research priority setting conducted?
North America - USA

Why was it conducted at all?
The growing number of families impacted by Alzheimer's disease and related dementias (ADRD), coupled with the lack of disease-modifying therapies, under scores the urgent need for research that addresses priorities in care for families. Bringing the perspective and expertise of families who have the lived experience of dementia to our research is important to the creation of evidence that matters and is beneficial to patients and families.

What was the objective?
to partner with stakeholders to identify gaps in care and from this list to identify priorities for dementia care research

What was the outcome?
a list of 19 research topics

How long did the research prioritization take?
August 2020 - October 2020

Which methods were used to identify research priorities?
group discussion; survey

How were the priorities for research identified exactly?
Step 1: formation of stakeholder advisory council (SAC). Step 2: initial generation of list of gaps in care and topics important to research. Step 3: SAC outreach to their networks about gaps in care and research topics, via symposium, webinars, and an online learning community. Step 4: small group discussion at annual symposium to add gaps to list. Step 5: compilation of long list of 86 research topics/questions. Step 6: review of long list: sub-group of SAC members, consisting of 2 researchers, a family caregiver, and 2 clinicians, review the long list, common ideas were merged, duplicates were removed, and wording was revised for clarity. Step 7: final survey: list of 46 items, participants were asked to rate the importance of each research topic area grouped into 7 overarching research domains

Which stakeholders took part?
Survey: 186 participants: 23 (12.4%) persons living with dementia, 101 (54.3%) family caregivers, 62 (33.3%) health/social care professionals of which majority (n=41, 66.1%) were health and social care professionals, 4 healthcare students, 17 other (paid caregivers, researchers, elder lawyers).

How were stakeholders recruited?
Those eligible to complete the survey were individuals who were personally or professionally impacted by dementia. This included PLWD, family caregivers, and professionals who worked directly or indirectly with families affected by dementia. A snowball sampling technique was used to recruit participants. Surveys were completed both through an electronic link to the Qualtrics survey and 'face-to-face' via Zoom. Face-to-face surveys were offered to PLWD and were administered by community members and members of the research team.

Were stakeholders actively involved or did they just participate?
Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of an advisory board. The advisory board consisted of 15 members: 2 patients, 4 family caregivers, 7 health/social care professionals, and 2 researchers. Professional members included geriatricians, a nurse with expertise in palliative care, social service program providers, and a member from the faith community. Members held monthly meetings and virtual zoom meetings. The meetings were designed to build capacity among members to participate in patient-centered outcomes research.