ORIGINAL RESEARCH

Engaging People With Lived Experience of Dementia in Research: Perspectives From a Multi-disciplinary Research Network

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ABSTRACT

Background

Patient and public involvement/engagement in research on dementia is not new, but it is becoming increasingly common. The objective of this study was to describe researchers' knowledge, attitudes, and activities related to engaging people with lived experience of dementia in research, and how these differ by research theme.

Methods

Data were from an online, anonymous survey of researchers within the Canadian Consortium on Neurodegeneration in Aging.

Results

Of the 84 researchers who completed the survey (response rate: 27%), 89% agreed they understood the meaning of engaging people with lived experience in research, although this was lower among biomedical researchers. Almost all (93%) agreed that people with lived experience could contribute meaningfully to research, and nearly two-thirds were already incorporating engagement in their research. Some engagement practices reported differed by research theme. Irrespective of the type of research they conduct, researchers were most often motivated by improving the relevance and quality of their research.

Conclusions

These findings support an optimistic outlook for engaging people with lived experience of dementia in research, but identify differences across research themes. Understanding approaches to incorporate, evaluate, and adapt engagement activities across research disciplines are needed to enable researchers, as well as others involved in research, to develop and target strategies for patient and public involvement/engagement in research on dementia.

Key words: dementia, research methodology, patient-oriented research, patient engagement

INTRODUCTION

Patient engagement in research on dementia is not new, but it is becoming increasingly common.(1) Advocacy by people living with dementia, researchers, and organizations, coupled with research funding mechanisms with a mandate to stimulate patient and public engagement, have created roles in research for people with lived experience of dementia beyond that of study subject. Researchers of all types (i.e., including biomedical, clinical, health services, and social, cultural, environmental, or population health) are being encouraged to reflect on and improve the way that they approach engaging people with lived experience in the context of research on dementia.(2)

Aside from the compelling moral and ethical motivations for engaging people with lived experience in research, evidence to support methodological advantages is also emerging.(3) However, while evaluation frameworks exist,(4) research demonstrating the impact is scarce, and approaches for incorporating, evaluating, and adapting engagement activities in different types of research are not well-defined. For biomedical and pre-clinical research, particularly, engagement is considered feasible(5) but challenging.(6)

The Canadian Consortium on Neurodegeneration in Aging (CCNA) is a network of over 300 dementia researchers and clinicians across Canada conducting biomedical, clinical, health services, and/or population health research.(7) CCNA research is organized into 19 teams nested within three research themes (prevention, treatment, and quality of life). The CCNA also has cross-cutting programs, including a recently established program to foster engagement of people with lived experience of dementia in research, built in partnership with, and supported by, the Alzheimer Society of Canada. The objective of this study was to describe CCNA researchers' knowledge, attitudes, and activities related to engaging people with lived experience of dementia in research, and how these differ according to the primary type of research conducted.

METHODS

This is a secondary analysis of an online, cross-sectional survey (Hosted in Canada Surveys platform; https://www.hostedincanadasurveys.ca/) conducted by the CCNA's Engagement of People with Lived Experience of Dementia cross-cutting program to assess CCNA researchers' knowledge, attitudes, and activities related to engaging people with lived experience of dementia in research. This study was approved by the University Health Network Research Ethics Board (20-5459).

The questionnaire was developed from previous research(8) and an online decision tool,(9) and in consultation with the CCNA and Alzheimer Society of Canada (Appendix A). The survey was developed in English then translated into French. Only two questions triggering skip patterns were mandatory. The rest were optional. Data were anonymous and no demographics were collected, minimizing possibility of re-identification.

The survey was not password-protected, but survey links were provided only to CCNA-affiliated researchers by email in September 2019, with reminder emails in November 2019. Data were collected between September and December 2019. No incentives were provided for participation.

Participants were asked to report their knowledge, attitudes, and activities related to engaging people with lived experience of dementia in research. They were also asked to report their primary type of research (biomedical; clinical; health services; social, cultural, environmental, or population health research) and Common Alzheimer's and Related Dementias Research Ontology (CADRO) category(10) best describing their research.

Descriptive analyses consisted of cross-tabulations (frequencies and proportions with 95% CIs), analyzed with Fisher's exact tests ($p < .05$) to test the association between research type and responses. Analyses were conducted in R (R Foundation for Statistical Computing; https://www.r-project.org/foundation/).

RESULTS

Eighty-four people completed questionnaires (27% of 311 researchers invited), with 10 surveys completed (12%) in French. The most common CADRO categories reported were: dementia care and impact of disease (n=36; 43%); translational research and clinical interventions (n=14; 17%); diagnosis, assessment, and disease monitoring (n=13; 16%); and brain aging and common mechanisms related to dementias (n=9; 11%).

Table 1 reports researcher knowledge, attitudes, and activities related to engagement of people with lived experience of dementia in research overall and by research type. Knowledge related to engaged research was high, with 89% of researchers agreeing or strongly agreeing they understood what engagement of people with lived experience of dementia means. There were differences in self-reported understanding of what engagement means across research types (p = .042), with lowest levels reported amongst biomedical researchers and highest levels amongst health services researchers.

Most respondents (93%) agreed or strongly agreed that people with lived experience could contribute meaningfully to the research process, with no differences by research type (p = .087) (Figure 1). Nearly two-thirds of respondents reported engaging people with lived experience in their research, and another quarter were interested in opportunities to do so, with no differences by research type (p = .127).

The most frequently indicated reasons for engaging people with lived experience were to make research more relevant (91%), improve the quality of research (85%), and empower people living with dementia (78%) (Table 2). The reasons cited did not differ significantly by research type.

More respondents reported engaging people with lived experience through activities preceding (priority setting, 63%) and following (knowledge translation, 76%) the research process. When aspects of study execution were considered together (i.e., study design and procedures, recruitment, data collection and analysis), this was the most common phase of engagement overall (n=48; 89%), as well as for each of biomedical (n=4; 100%), clinical (n=20; 91%), health services (n=18; 86%) and social, cultural, environmental, and population health (n=6; 86%) research. However, regarding the questions of how respondents engaged people with lived experience differed by research type, biomedical researchers were less likely to report engaging people with lived experience in priority setting (p = .004), but more likely to report engagement in data collection (p = .009).

A minority (9 of 84) of respondents indicated they did not engage people with lived experience and had no interest in doing so. The most commonly cited reasons were lack of relevance for their area of research (6/9 respondents), difficulty finding people with lived experience who were 'representative' (2/9 respondents), and time and financial costs (2/9 respondents).

DISCUSSION

Results of this study suggest most CCNA researchers, irrespective of the type of research they conduct, agree that

TABLE 1.
Researcher self-reported knowledge, attitudes and current activities related to patient engagement in research on dementia, overall and stratified by research theme

	Research Theme									
	Total/Overall (n=84)		*Biomedical (n=10)*		*Clinical (n=35)*		*Health services (n=27)*		*Social, Cultural, Environmental, Population Health (n=12)*	
In the context of research, I understand what engagement of people with lived experience of dementia means.	n	%col (95% CI)	n	%col (95% CI)	n	%col (95% CI)	n	%col (95% CI)	n	%col (95% CI)
Strongly agree	27	33 (22–43)	1	11 (0–32)	17	49 (32–65)	7	26 (9–42)	2	17 (0–38)
Agree	47	57 (46–67)	6	67 (36–97)	14	40 (24–56)	19	70 (53–88)	8	67 (40–93)
Neither agree nor disagree	5	6 (1–11)	1	11 (0–32)	3	9 (0–18)	1	4 (0–11)	0	0
Disagree	2	2 (0–6)	0	0	1	3 (0–8)	0	0	1	8 (0–24)
Strongly disagree	2	2 (0–6)	1	11 (0–32)	0	0	0	0	1	8 (0–24)
Missing (n=1)										
In general, people with lived experience of dementia can contribute meaningfully to the research process.										
Strongly agree	45	54 (43–64)	3	30 (2–58)	22	63 (47–79)	16	59 (41–78)	4	33 (7–60)
Agree	33	39 (29–50)	5	50 (19–81)	11	31 (16–47)	11	41 (22–59)	6	50 (22–78)
Neither agree nor disagree	5	6 (1–11)	2	20 (0–45)	2	6 (0–13)	0	0	1	8 (0–24)
Disagree	0	0	0	0	0	0	0	0	0	0
Strongly disagree	1	1 (0–4)	0	0	0	0	0	0	1	8 (0–24)
Does your research already include engagement of people with lived experience of dementia?										
Yes	54	64 (54–75)	4	40 (10–70)	22	63 (47–79)	21	78 (62–93)	7	58 (30–86)
No, but interested	21	25 (16–34)	3	30 (2–58)	9	26 (11–40)	6	22 (7–38)	3	25 (1–50)
No, and not interested	9	11 (4–17)	3	30 (2–58)	4	11 (1–22)	0	0	2	17 (0–38)

CI = confidence interval.

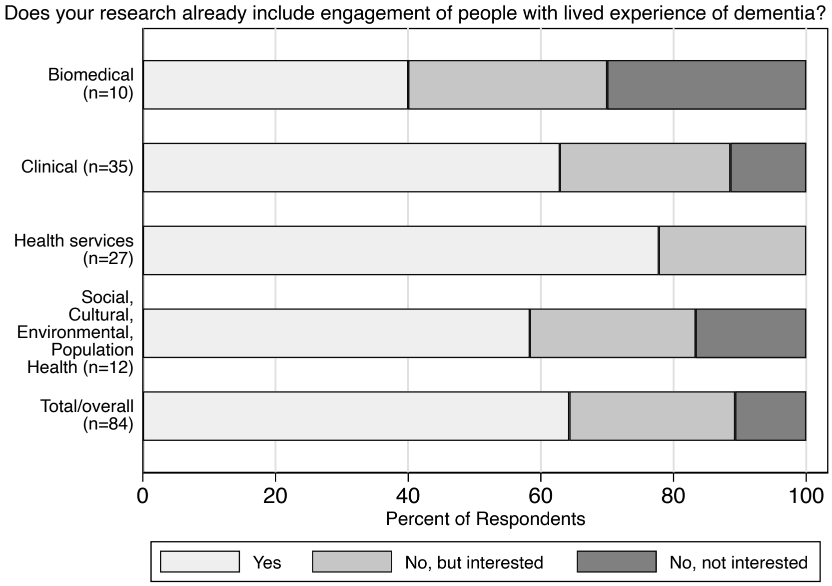

FIGURE 1. Researcher-reported engagement of people with lived experience of dementia in research, overall and by research theme

Table 2.
Researcher self-reported reasons for and capacity in which they engage persons with lived experience of dementia in research, overall and stratified by research theme

			Research Theme							
	Total/Overall (n=54)		*Biomedical (n=4)*		*Clinical (n=22)*		*Health services (n=21)*		*Social, Cultural, Environmental, Population Health (n=7)*	
Why do you engage people with lived experience of dementia in your research? (select all that apply)	n_{yes}	$\%_{yes}$ (95% CI)	n_{yes}	$\%_{yes}$ (95% CI)	n_{yes}	$\%_{yes}$ (95% CI)	n_{yes}	$\%_{yes}$ (95% CI)	n_{yes}	$\%_{yes}$ (95% CI)
To make the research more relevant	49	91 (83–98)	2	50 (1–99)	20	91 (79–100)	20	95 (86–100)	7	100
To improve the quality of the research	46	85 (76–95)	2	50 (1–99)	20	91 (79–100)	19	90 (78–100)	5	71 (38–100)
To empower people who have lived experience of dementia	42	78 (67–89)	2	50 (1–99)	17	77 (60–95)	17	81 (64–98)	6	86 (60–100)
To make me a better researcher	33	61 (48–74)	1	25 (0–67)	13	59 (39–80)	13	62 (41–83)	6	86 (60–100)
It's the democratic and fair thing to do	21	39 (26–52)	1	25 (0–67)	9	41 (20–61)	7	33 (13–53)	4	57 (20–94)
To keep up with the demands of research funding organisations and journals	18	33 (21–46)	2	50 (1–99)	9	41 (20–61)	4	19 (2–36)	3	43 (6–80)
In what capacity are people with lived experience of dementia engaged in your research? (select all that apply)										
Governance	11	20 (10–31)	0	0	5	23 (5–40)	4	19 (2–36)	2	29 (0–82)
Priority setting	34	63 (50–76)	0	0	12	55 (34–75)	18	86 (71–100)	4	57 (20–94)
Study design and procedures	25	46 (33–60)	0	0	9	41 (20–61)	13	62 (41–83)	3	43 (6–80)
Study recruitment	28	52 (39–65)	3	75 (33–100)	13	59 (39–80)	9	43 (22–64)	3	43 (6–80)
Data collection	18	33 (21–46)	4	100	5	23 (5–40)	5	24 (6–42)	4	57 (20–94)
Data analysis	21	39 (26–52)	1	25 (0–67)	8	36 (16–56)	10	48 (26–69)	2	29 (0–62)
Knowledge translation	41	76 (65–87)	1	25 (0–67)	16	73 (54–91)	18	86 (71–100)	6	86 (60–100)

CI = confidence interval.

people with lived experience of dementia can meaningfully contribute to research and are enthusiastic about engaging people with lived experience of dementia in their research. Overall, researchers felt they had a good understanding of engaged research, but this was lowest amongst biomedical researchers. Consistent with previous research,(11,12) researchers were motivated to conduct engaged research to improve the quality and relevance of their research and empower people with lived experience of dementia.

These data show that researchers most often engaged people with lived experience in study execution (i.e., one or more of study design and procedures, study recruitment, data collection, and data analysis); this finding corroborates a systematic review of patient-engaged research (not restricted to research on dementia)(13) and a scoping review of patient engagement in research on dementia,(1) both of which found that the most common phase for engagement was study execution. However, the current data also demonstrated specific roles sometimes differed by type of research. While engagement of people with lived experience sometimes consists of a "one-off" activity, researchers are encouraged to initiate engagement at the earliest opportunity and pursue continuous engagement throughout the research process.(2) Regardless of research type, sustained engagement throughout the research process may reduce feelings of "tokenism", a deterrent to patient-engaged research for both people with lived experience and researchers.(11,14-16)

To our knowledge, this was the first study to examine knowledge, attitudes, and activities related to engagement of people with lived experience of dementia in a multidisciplinary network of dementia researchers. However, we acknowledge the low response rate and likely impact of selection bias. Those who already conduct, or are interested in conducting, engaged research may have been more likely to participate in the survey. Thus, our results may present an overly enthusiastic characterization of researchers' knowledge, attitudes, and activities related to engaging people with lived experience of dementia in research.

CONCLUSION

These findings support an optimistic outlook for building capacity in patient and public engagement in research on dementia. Most researchers are motivated to include people with lived experience of dementia in their research. However, our findings demonstrate engagement activities differ by type of research. A better understanding of approaches to incorporate, evaluate, and adapt engagement across different types of research is needed. Moving forward, working in partnership with the Alzheimer Society of Canada, the CCNA has established an Advisory Group (www.epled.ca) to build opportunities for engaging people with lived experience of dementia in CCNA research. Through such initiatives, further research and evaluation activities will help enable researchers to develop and implement strategies to engage people with lived experience of dementia in research.

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CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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APPENDIX A. Survey on Patient Engagement Amongst Researchers in the Canadian Consortium on Neurodegeneration and Aging

The Canadian Institutes of Health Research (CIHR) defines patient engagement as: "Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context patient-oriented research may also engage people who bring the collective voice of specific, affected communities."

Patients include individuals with personal experience of a health issue and informal caregivers, including family and friends. We use the phrase "lived experience" to acknowledge that, in this situation, the term patient may not meet person-centred language guidelines. Accordingly, in the context of research on dementia, we will hereafter refer to "patient engagement" as "engagement of people with lived experience of dementia".

Section A:

A1. Please rate your responses to the following statements.

	Strongly disagree	*Disagree*	*Neither agree nor disagree*	*Agree*	*Strongly agree*
In the context of research, I understand what engagement of people with lived experience of dementia means.					
In general, people with lived experience of dementia can contribute meaningfully to the research process.					

A2. Does your research already include engagement of people with lived experience of dementia?

- ☐ Yes <<MOVE TO SECTION B>>
- ☐ No <<SKIP TO SECTION E>>

Section B:

B1. Why do you engage people with lived experience of dementia in your research?

- ☐ To improve the quality of the research
- ☐ To make the research more relevant
- ☐ To make me a better researcher
- ☐ To empower people who have lived experience of dementia
- ☐ It's the democratic and fair thing to do
- ☐ To keep up with the demands of research funding organisations and journals

B2. Are there any other reasons you engage people with lived experience of dementia in your research?

B3. In what capacity are people with lived experience of dementia engaged in your research?

- ☐ Governance
- ☐ Priority setting
- ☐ Study design and procedures (e.g. selecting outcomes, reviewing consent procedures and study documents, etc.)
- ☐ Study recruitment
- ☐ Data collection
- ☐ Data analysis (including interpretation of findings)
- ☐ Knowledge translation

B4. Please describe some specific ways in which you have engaged people with lived experience of dementia in your research (e.g., developing consent forms for my clinical study, contextualizing results from my systematic review, being involved in my CIHR-SPOR funding applications, preparing lay summaries when I publish my research results, etc.)

B5. Do you engage people with lived experience of dementia in your CCNA research?

- ☐ Yes – and only in my CCNA research
- ☐ Yes – in my CCNA research and also in my non-CCNA research
- ☐ No – my engagement activities are related to my non-CCNA research

B6. Are you interested in other ways to engage people with lived experience of dementia in your CCNA research?

- ☐ Yes
- ☐ No

Section C:

C1. Are you interested in engaging people with lived experience of dementia in your CCNA research?

- ☐ Yes
- ☐ No

Section D

D1. Why are you interested in engaging people with lived experience of dementia in your CCNA research?

- ☐ To improve the quality of the research
- ☐ To make the research more relevant
- ☐ To make me a better researcher
- ☐ To empower people who have lived experience of dementia
- ☐ It's the democratic and fair thing to do
- ☐ To keep up with the demands of research funding organisations and journals

D2. Are there any other reasons you are interested in engaging people with lived experience of dementia in your research?

D3. In what capacity would you like to engage people with lived experience of dementia in your CCNA research?

- ☐ Governance
- ☐ Priority setting
- ☐ Study design and procedures (e.g. selecting outcomes, reviewing consent procedures and study documents, etc.)
- ☐ Study recruitment
- ☐ Data collection
- ☐ Data analysis (including interpretation of findings)
- ☐ Knowledge translation

D4. Please describe some specific ways in which you would like to engage people with lived experience of dementia in your research (e.g., developing consent forms for my clinical study, contextualizing results from my systematic review, being involved in my CIHR-SPOR funding applications, preparing lay summaries when I publish my research results, etc.)

Section E:

E1. Why are you not interested in engaging people with lived experience of dementia in your CCNA research? Select all that apply.

- ☐ It's not relevant for my area of research
- ☐ People with lived experience of dementia lack the training required for engaging in my area of research
- ☐ The time and financial costs associated with engagement activities make it impractical
- ☐ I think my Research Ethics Board would have problems with it
- ☐ I don't know how to find people with lived experience of dementia who are interested in being engaged in my area of research
- ☐ It would be difficult to find people with lived experience of dementia who are 'representative'
- ☐ I'm concerned about tokenism
- ☐ There is no evidence that it has a positive impact

E2. Are there any other reasons you are not interested in engaging people with lived experience of dementia in your research?

Section F:

F1. In general, thinking about all the research being done within the CCNA, what do you think are the barriers to engaging people with lived experience of dementia in CCNA research and how could they be addressed?

F2. In general, thinking about all the research being done within the CCNA, what do you think would be effective strategies and resources for engaging people with lived experience of dementia in CCNA research?

F3. Are you aware of the following resources?

- ☐ Meaningful engagement of people with dementia (Alzheimer Society of Canada)
- ☐ Considerations when paying patient partners in research (CIHR SPOR)
- ☐ Should money come into it? (The Change Foundation)
- ☐ Patient engagement framework (CIHR SPOR)
- ☐ Choosing a dementia-friendly meeting space (The Dementia Engagement and Empowerment Project)
- ☐ Core principles for involving people with dementia in research: innovative practice (Scottish Dementia Working Group)
- ☐ Developing training and support for public involvement in research (INVOLVE)
- ☐ Briefing notes for researchers: public involvement in NHS, public health and social care research (INVOLVE)
- ☐ Public involvement in clinical trials (INVOLVE)
- ☐ Public involvement in systematic reviews (INVOLVE)
- ☐ Strategies for diversity and inclusion in public involvement (INVOLVE)

Section G:

G1. What CCNA team(s), program(s) and platform(s) are you involved with?

- ☐ Theme 1: Prevention (teams 1-5)
- ☐ Theme 2: Treatment (teams 6-13)
- ☐ Theme 3: Quality of Life (teams 14-19)
- ☐ Indigenous Cognitive Health Program
- ☐ Knowledge Translation and Exchange (KTE)
- ☐ Ethical, Legal and Social Issues (ELSI)
- ☐ Women, Sex, Gender and Dementia (WSGD)
- ☐ Training and Capacity Building (TCB)
- ☐ COMPASS-ND
- ☐ LORIS
- ☐ CAN-THUMBS UP
- ☐ Neuroimaging

G2. What is your role within the CCNA?

- ☐ Research Executive Committee (REC) Member
- ☐ Cross-Cutting Program Leader (ELSI, TCB, WGSD or KTE)
- ☐ Platform Leader (COMPASS-ND, LORIS, CAN-THUMBS UP or Neuroimaging)
- ☐ Theme Leader (Prevention, Treatment or Quality of life)
- ☐ Team Leader
- ☐ Researcher
- ☐ Trainee (Master’s, PhD or postdoctoral)

Thank you for your participation!