

New Insights for People Affected by Posterior Cortical Atrophy in Canada

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Background

- ❖ For individuals living with posterior cortical atrophy (PCA), a condition commonly associated with the pathology of Alzheimer's disease,¹ obtaining a diagnosis and transitioning to post-diagnostic support can be especially difficult.² These challenges are driven by a limited understanding of visuo-spatial and visuo-perceptual impairments, their functional and psychosocial impact, few tailored diagnostic, rehabilitation and support services, and a lack of understanding of what effective compensatory strategies work.^{3,4}
- ❖ PCA clinical care or support pathways do not yet exist in most jurisdictions. And despite growing awareness of PCA, dementia-related content in health education curricula is either absent or delivered through a generalist approach.^{3,4}
- ❖ In Canada specifically, support for families affected by PCA and other rare dementias has only recently received attention, like trends observed in other countries worldwide.⁴

Objectives

1. Generate insights to inform support delivery (e.g., informational, environmental, bio-psychosocial) for people living with dementia-related visual impairment.
2. Inform an education strategy on dementia-related visual impairment (i.e., inclusive of PCA).
3. Identify priorities for support, rehabilitation services and evaluation.

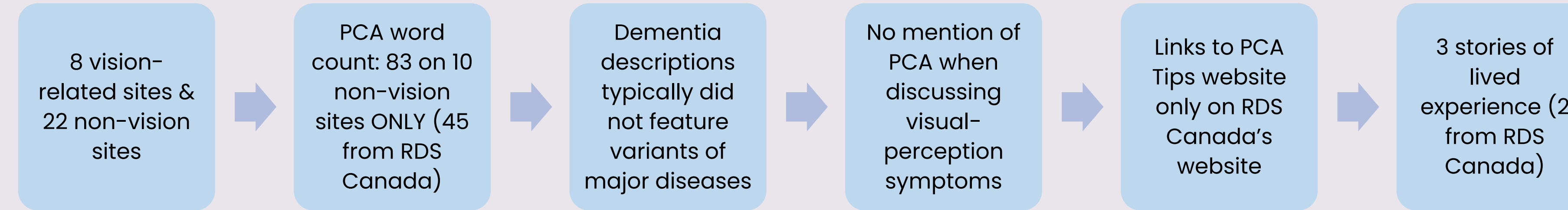
Methods

- ❖ A multi-disciplinary, intersectoral user-involved working group ($n = 16$) was formed to plan and oversee the development of this mixed method investigation.
- ❖ **Data Collection**
 - Literature synthesis ($n = 14$ articles)
 - National practitioner survey ($n = 68$) → follow-up interviews with a sub-sample of practitioners ($n = 5$)
 - Focus group ($n = 7$) and interviews with persons living with PCA and/or their family supporter ($n = 6$)
 - Environmental scan ($n = 30$ organizations)
 - Key informant consultations ($n = 11$)
- ❖ **Data Analysis**
 - Descriptive statistical analysis using JASP
 - Thematic analysis following Braun & Clarke⁵

Results

1. Environmental Scan

- 30 organizations were identified and data were extracted from their website



2. Practitioner Survey

- 118 responses received; reduced to 68 after data cleaning
- Most respondents were:
 - women (86.6%)
 - between the ages of 15-34 (26.5%) and 45-54 (29.4%)
 - within the public healthcare sector (57.4%)
 - had over 10 years of work experience (56.1%)
- Practitioners were asked to rate their confidence (5-point Likert scale) (Figure 1 & 2)
- non-vision specialists (e.g., nurse, occupational therapist, social worker, etc.) (65.2%)
- lived in Ontario (55.9%)

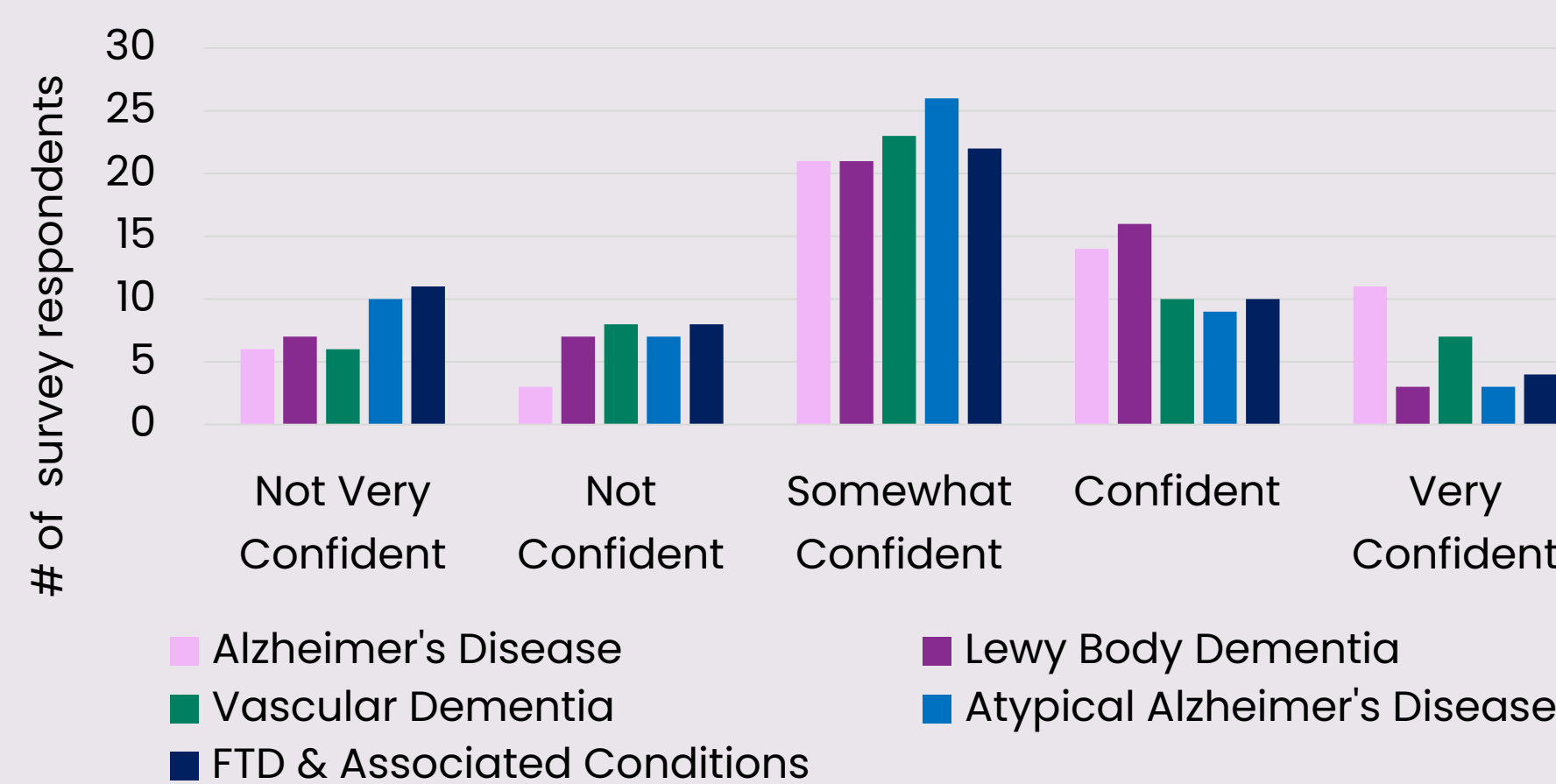


Figure 1: Practitioners' confidence varied across different types of dementia. Most practitioners reported feeling somewhat confident in supporting people with all types of dementia. However, Alzheimer's disease followed by vascular dementia were the areas where the greatest number of practitioners reported feeling very confident. FTD and Atypical Alzheimer's had the highest proportion of practitioners reporting low levels of confidence.

Supportive strategies identified by practitioners:

- Referrals to occupational therapists and vision rehabilitation specialists
- Use of adaptive equipment (e.g., communication board with photos) and environment modifications (e.g., large stickers on buttons such as the microwave)

3. Interviews and Focus Group

Practitioner Interviews: Emerging Themes

1. **Challenging pathways to diagnosis, post-diagnostic information & support**
"...because people with PCA are more physically able and mobile, sometimes their needs get overlooked...physicians not referring for rehab-type services...medical practitioners say nothing can be done." (social worker, northern Ontario)
2. **Lack of flexibility & understanding in long-term care**
"...the long-term care home was refusing to move the furniture to the perimeter of the room... so those kinds of rules that really butt up against what someone with PCA [needs]." (social worker, northern Ontario)
3. **Absence of skilled occupational therapists & specialized supports**
"It's very hard to find an OT in the community who has ever seen somebody with a diagnosis of PCA...I don't think they have specialist expertise. I think they are all sort of generalist in nature." (social worker, southern Ontario)

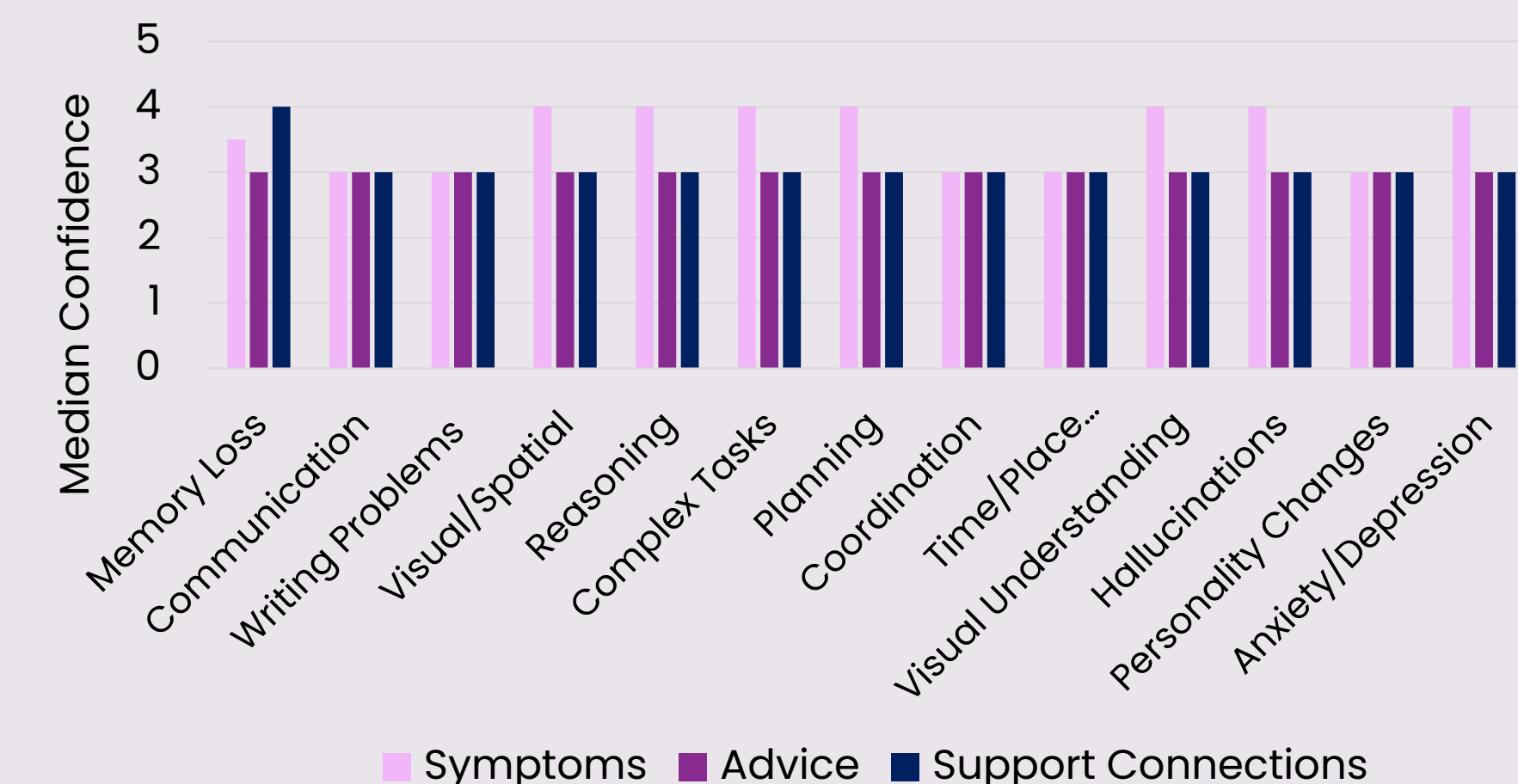


Figure 2: Practitioners confidence in supporting people with rare dementia and providing individuals and their families with advice and/or suggestions for support. Practitioners reported feeling somewhat confident (median confidence score) in identifying symptoms but were less confident in providing advice and/or connecting families to appropriate supports. Notably practitioners were most confident assisting families experiencing memory loss compared to any other dementia related symptom.

Barriers experienced by practitioners:

- No family support and/or lack of motivation by the person living with rare dementia
- Lack of training and/or resources (e.g., time, money, knowledge)

People affected by PCA: Emerging Themes

1. **Information following diagnosis**
"And if you, for example, are diagnosed with a cancer, there are multiple pathways available. Yes, pathways, yeah. Okay, same thing, if it applied to the dementias and recognized that there are different dementias, then, to me, that would be a gold mine. Because that's your information sort. It tells you the steps, it tells you what's happening in each of those steps, it tells you what you need to do." (male family supporter, eastern Ontario)
2. **Social engagement as important as visual aids**
"So, access to nature, so ability to get out, or even to see it from your window. The dog thing, I would concur with Sam, our dog is great, although, you know, it would have been great if we had sort of trained him like... and we got him after Terry's diagnosis, trained him like a seeing-eye dog." (female supporter, eastern Ontario)
3. **Professional education & accessible messaging**
"...I think it's kind of got to be someone who knows PCA, again, right? Because I had this gal, and I was so far out of her depths, like, there's no way she could...I think there needs to be channels of resources because it would have saved me a lot of grief...it was upsetting and lots of stuff, like, to work through." (female living with PCA, central Alberta)

Discussion

- ❖ Many people affected by PCA in Canada live with uncertainty and anxiety due to:
 - Obstacles in obtaining a diagnosis
 - Lack of knowledge of PCA-related visual impairment among different practitioner groups
 - Non-existent pathways to post-diagnostic support
 - Limited access to skilled vision specialists and aids in most jurisdictions across the country
- ❖ Individuals and families affected by PCA require tailored and continuous support that responds to the unique challenges associated with PCA while also addressing their overall psychosocial well-being.
- ❖ Targeted education for vision specialists and other relevant practitioners could improve awareness of PCA-related visual impairment and encourage more appropriate referrals for rehabilitation, support and care planning.

Conclusions

- ❖ Timely diagnosis and appropriate tailored support would minimize the uncertainty and anxiety that people affected by PCA experience given the current organization of health services for people living with dementia.
- ❖ Closer collaboration between specialist dementia-related and specialist vision-related services could improve access to coordinated, tailored support for people affected by PCA.

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Check out our website for more information

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This study has been approved by the Nipissing University Research Ethics Board: NUREB # 10389