

Rare And Young Onset Dementia: Supporting Family Life

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Background

Rare Dementia Support (RDS) Canada is a support community for people living with rare and young onset dementia (PLWrD) and a centre for research and education. It is part of a growing global community recognizing the unique support needs of those affected and the gaps in existing care and support services. RDS Canada’s multi-component support model and theory of change was developed in 2019–24 with colleagues in the UK¹. RDS Canada is currently progressing with development activities to scale support delivery and improve access and uptake across geography, strengthen our evidence-informed model for diverse families and family structures, and enhance capacity for the provision of accessible and inclusive supports.

Aims

As part of a realist evaluation of RDS Canada, our aim was to generate insights specific to the impact of rare and young onset dementia on the entire family system and how families sustain care and support over time. Our research questions included:

1. What support [short and long term] is most effective for diverse family/friendly structures and family/friendly members (e.g., children/youth, spouses/partners, parents, parents-in-law, siblings, close friends)?
2. What support [short and long term] is most effective for families with diverse socio-cultural identities?
3. How do these families implicitly and/or explicitly negotiate caring and support roles, facilitate decision-making and manage conflict during periods of transition and/or over time?

Methods

Purposefully recruited from RDS Canada’s membership, we undertook 12 family case studies*. Data was collected virtually using multiple methods including:

- Initial interview to obtain socio-demographic characteristics and complete standardized measures (e.g., Dementia Severity Rating Scale²).
- Family interview to explore individual and generation experiences
- Individual interview facilitated by mapping the ecology of support connections
- Final interview facilitated by family scrapbooking to contextualize family life

Our analytical approach was informed by Bruan and Clarke’s (2022) thematic analysis.³ We generated thematic codes to develop theoretical insights into family functioning and support needs, and further insights into our program theory consistent with realist evaluation. We report here on the former only. Ethics approval was obtained by the Nipissing University Research Ethics Board (#103839).

*The study followed Widmer’s (2010) definition of family as “sets of directly or indirectly interdependent person sharing feeling of family belonging and connectedness” (pg. 30).⁴

Findings

We recruited a total of 56 participants among 12 families (Table 1). The family structure and number of research participants varied among each (Figure 1).

Family #	Diagnosis	PLWrD age at diagnosis	PLWrD Participation (Y or N)	Ethnic/Cultural Identification	Family Structure (e.g., childless, remarriage)
Family 1 (n=4)	bvFTD	64	No	Black – Afro-Caribbean	Married with adult children
Family 2 (n=1)	LBD	62	No	White	Remarried with adult children
Family 3 (n=7)	bvFTD	69	No	White	Remarried with adult children
Family 4 (n=3)	PCA	54	No	White	Married with young children
Family 5 (n=2)	PCA	67	Yes	White	Married with no children
Family 6 (n=3)	PCA	57	Yes	White	Married with young children
Family 7	Dropout	Dropout	Dropout	Dropout	Dropout
Family 8 (n=5)	FTD	62	Yes	White	Married with young children
Family 9 (n=9)	PPA	54	Yes	White	Remarried with adult children
Family 10 (n=4)	PPA	62	Yes	White	Married with adult children
Family 11 (n=6)	PCA	71	Yes	White	Married with adult children
Family 12 (n=9)	PPA	73	Yes	White – Jewish	Married with adult children
Family 13 (n=3)	PPA	30	No	White	Divorced with young child

Table 1. Participants

Our data portrayed both complex family structures, relationships and practices that were interrupted when someone was living with rare dementia (Figure 2). Key themes emerging from the multiple data sources included:

Defining rare dementia support across the family system: Families described support in multiple ways, reflecting the diverse needs and roles within the family system. A broad range of support was identified and ranged from, for example, meaning making psychotherapy to access to green spaces for leisure activities.

“Yeah. Yeah, for sure, since a kid, I’ve loved camping. Every... yeah, every... year ... since cubs... And that’s the, yeah, that’s that outdoor activity, nature-focused, and doing it with, with peers, and all that kind of stuff.” (PLW-PCA)

Diverse impacts across family members: Rare and young onset dementia affected family members in different ways depending on family history, relationships, roles, life stage, and level of involvement in care and support over time. Both spoken and unspoken perspectives on the disease impact varied across the family system.

“And I want to be there and help take care of her [my mom with PCA] and help alleviate things for my dad, who’s doing so so much. But he [my dad] is very insistent that I, because it was what my mom wanted for me, like they want me out in [City] doing my shows, meeting people, going to school. But also I feel like I I can’t cause like my mom. She is part of me, and I can’t just like go off and live my, my twenties lifestyle. I want to be there for her I want every chance I have to be there with her, to hang out with her, to just sit around with her.” (Female family supporter, daughter of PLW-PCA)

Timely transition to tailored post-diagnostic support and rehabilitation: Unsurprisingly, key family supporters emphasized the value of being linked to tailored support or rehabilitation as soon as possible following a diagnosis rather than generalist dementia services was valued. Support for children, siblings and parent were also identified as problematic which reinforced the popular concept of only one principal care partner rather than multiple.

“...when we got the diagnosis, we were just like, that’s all we got. We didn’t get any information or pamphlets on the dementia, the symptoms, like, what to do next other than to call [Dementia charity A]. We had to do all the research. And then, I think, the next time we saw her– her geriatric psychiatrist, they did go through some of the symptoms, but that was weeks later.” (Female family supporter, daughter of PLW-bvFTD)

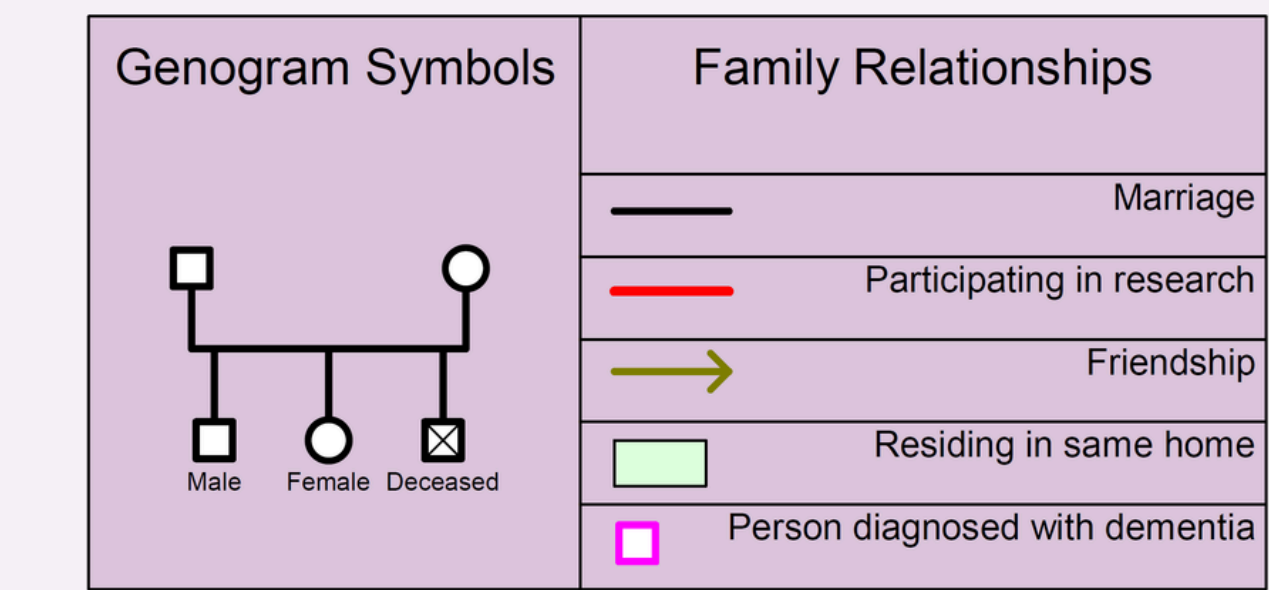
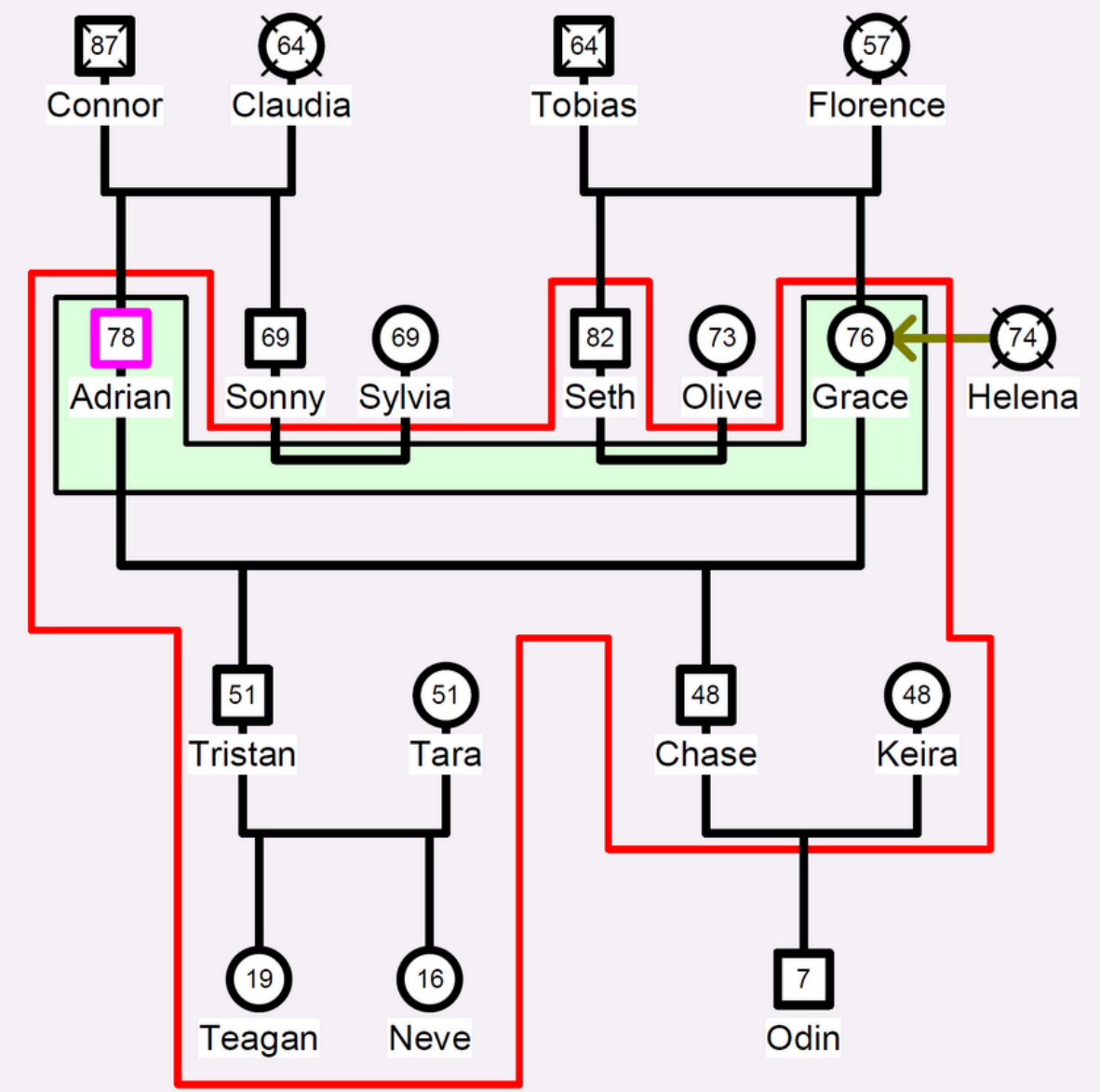


Figure 1. Genogram

Extensive support labour: Families described the substantial work required to sustain care and support over time, including ‘supplementary work’ generated by accessing support (e.g., challenging dementia narratives, applying new knowledge in practice). This labour was shaped by family context and extended beyond the primary supporter through both explicit and implicit arrangements across wider support networks.

“I’m blessed that I have the background, and that I know how to massage the system sometimes a little bit more than the average Joe might. So I’m grateful for that. But yeah, I always worry about the person with, you know, with the least ability to advocate. And everybody needs to advocate for their loved one. I think that’s our biggest role as care partners is to, to be the squeaky whip. And [it’s] tough, because, as you said, dementia is highly stigmatized.” (Female family supporter, spouse of PLW-LBD)

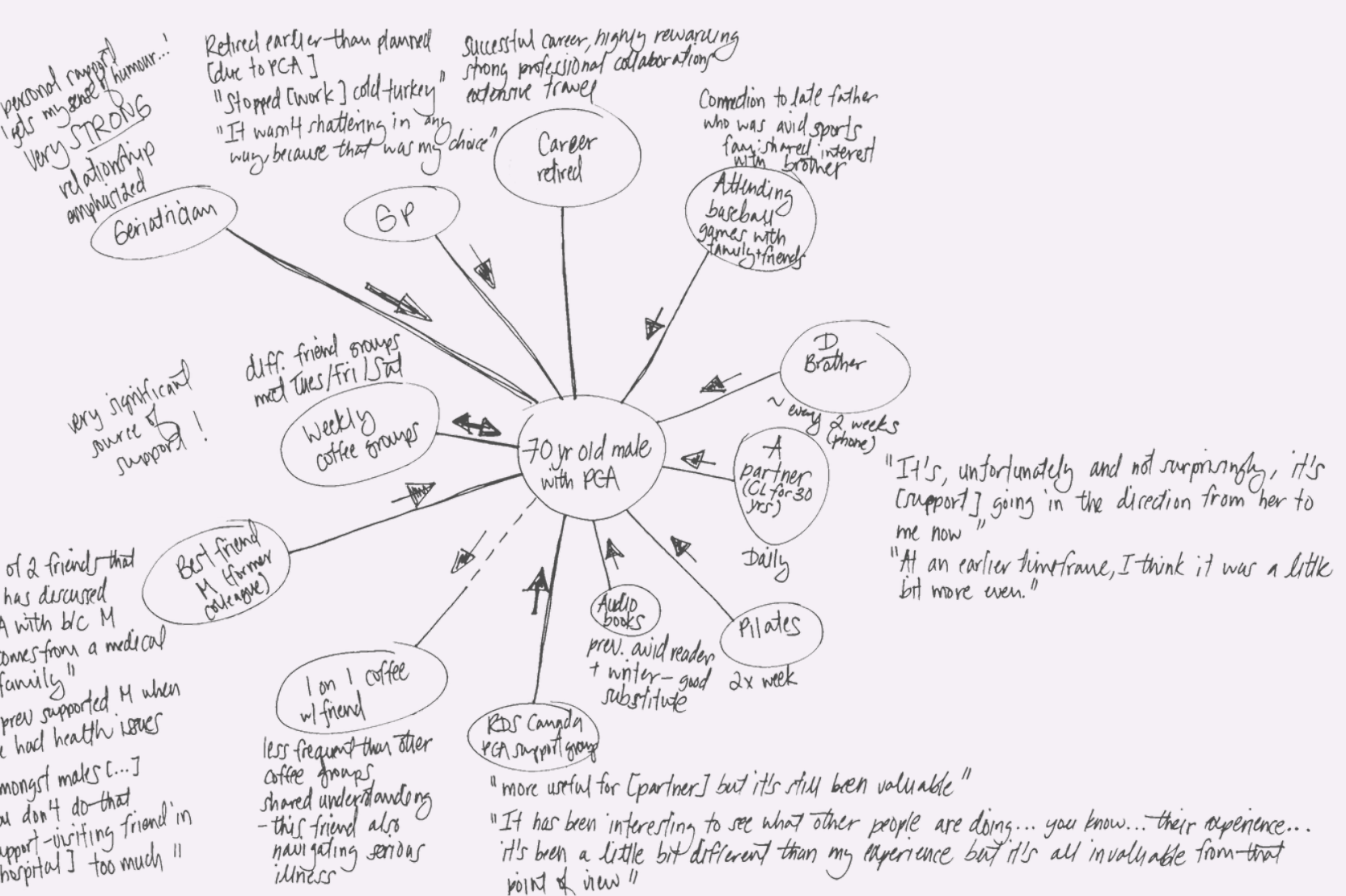


Figure 2. Ecomap

*Straight line is a positive/strong connection
Dashed line is a intermediate connection
Direction of arrow indicates direction of energy

Discussion

Our findings are consistent with the literature on family-centred support models⁶ and Rolland’s Family System Illness Model.⁷ We expanded these insights in the context of rare and young onset dementia, highlighting several key considerations:

- Respectful and flexible family engagement tailored to individual family members as well as the family system to sustain emotional and mutual connection.
- Genuine and substantive recognition of the work embedded in family support practices.
- A personalized and family-centred support plan should include a broad range of options that can be adjusted over time.
- Psychoeducation as a form of support grounded in the daily life of the different family systems and capture both disease and family transitions.

Conclusion

Our interest in promoting resilience in family systems affected by rare and young onset dementia necessitates timely, generation-specific supports, that are grounded in family strengths to facilitate healthy adaptation across the trajectory of the illness.

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