

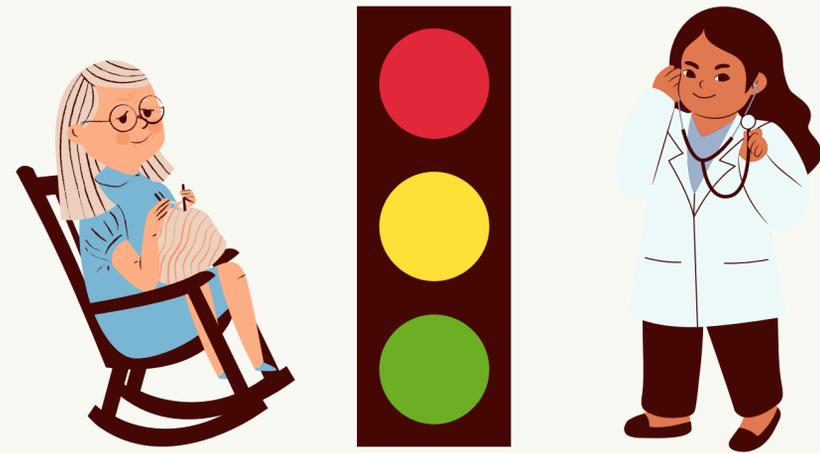
Exploring barriers and facilitators to dementia care in New Brunswick

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OBJECTIVE

The purpose of this study is to explore barriers and facilitators to dementia diagnosis and post-diagnostic support from the perspective of persons with dementia (PWD) and their care partners (CP) such as family members or friends, as well as health and social care providers (HSCP) in New Brunswick.

METHODS

Semi-structured individual interviews and focus groups were conducted with CP (n=14), PWD (n=5), and HSCP (n=9). Qualitative interview data were analyzed in NVivo using Braun and Clarke's (2006) six phases of thematic analysis.

KEY BARRIERS AND FACILITATORS

Barriers that emerged related to diagnostic and post-diagnostic care include: **lack of access and support**, **'no continuity of care'**, **stigma**, and **caregiver burnout**. **Facilitators** included: **education**, **compassionate care**, **establishing a network of support**, **'upholding personhood' of PWD**, and **support to navigate the system**.

LACK OF ACCESS AND SUPPORT

Participants noted a lack of access to diagnostic and post-diagnostic care stemming from a variety of factors, such as income levels, suspension of services due to COVID-19, wait times due to understaffing of health and social care systems, New Brunswick's geography, living in rural areas, and language barriers.



CAREGIVER BURNOUT

Care partners emphasized the dangers of overworking themselves when taking care of a PWD, alongside the necessity of taking time to themselves to engage in self-care and tend to their own personal lives:

"If we're not taking care of ourselves, I guess that's where I'm really struggling. Um, because we're not good to them if we're not taking care of ourselves and [...] it's hard to take that time. [...] I think there has to be something put in place for our mental health as well. [...] Boundaries. Yeah."
 (Participant 2, CP)



ESTABLISHING A NETWORK OF SUPPORT

Establishing a network of support was seen as crucial by participants that referenced pulling together a group of informal care partners who work together to support a PWD:

"Get your support group AKA family involved in helping you. Um when people call up and say oh I've heard about the diagnosis, is there anything I can do? Yeah, have a list. And have it be very specific. Yes, you can make a meal for both of us the last Thursday of every month and bring it to us. That, and have your list together and don't be [imitates a voice] it's okay, we've got this [kind of person]. Don't. 'Cause it's a long haul thing."
 (Participant 12, CP)



'NO CONTINUITY OF CARE'

Participants cited fragmentation of diagnostic and post-diagnostic dementia care. This was often due to poor communication between different types of HSCPs, as well as poor communication with CPs. The quote below illustrates the difficulty that some CPs have faced:

"Everything starts from scratch. There's **no continuity of care** [...] I have to be on her (*referring to HCSP*) constantly, like I've been calling her and calling her and calling her and she doesn't get back to me, she doesn't respond."
 (Participant 7, CP)



EDUCATION

Education of HSCPs, CPs, and PWDs was viewed by participants as a facilitator with regards to breaking down stigma and common myths about dementia, as well as allowing for CPs and HSCPs to feel better equipped to support PWDs.



'UPHOLDING PERSONHOOD' OF PWD

Many HSCPs and CPs viewed maintaining the PWD's independence and dignity as integral to ensuring that PWDs receive compassionate care:

"Through **upholding personhood**, we're able not only to look at the physical body in the medical needs, but how do we socially and emotionally, um, support [PWD] so that they still feel like they have an identity and their identity is upheld through meaningful activities and meaningful ways of life."
 (Participant 7, HSCP)



STIGMA

Some CPs and PWD felt a sense of shame or embarrassment when asking for help or telling family and friends about their diagnosis, due to common misconceptions about dementia:

"I do have difficulty telling people that [I have dementia]. That's a really hard thing for me. [...] People they, they don't know what to do and they treat you differently and I don't like that."
 (Participant 3, PWD)



COMPASSIONATE CARE

Participants found empathy and appropriate bedside manner from HSCPs to be paramount to facilitating the diagnostic process, along with instilling a sense of hope in PWDs and CPs about their dementia diagnosis.



SUPPORT TO NAVIGATE THE SYSTEM

Alongside reference materials like pamphlets and websites, participants called for a patient navigator with whom they could regularly communicate with and voice any concerns or questions:

"I think at a time like [receiving dementia diagnosis] just somebody to arrive at their home to say 'So how are you doing?' [would be helpful]. Like I understand you've got this really tough diagnosis, and let's you know, what kinds of questions do you have right now? [...] And what can I do to facilitate some of the concerns you may have?"
 (Participant 7, CP)



DISCUSSION

Participants called for greater integration of dementia care and system navigation supports to fill in current gaps of dementia care. Ensuring that CP and PWD have consistent and regular access to formal emotional, practical, and medical support is crucial in eliminating barriers to dementia care in New Brunswick.