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nsca@msvu.ca homecarepathways.ca

Assumptions about Unpaid Support of Older Home Care Clients can be Problematic

Authors: Laura Funk, Kaitlyn Kuryk, Lauren Spring and Janice Keefe



THE SYNOPSIS

Researchers interviewed

53*PARTICIPANTS in two Canadian Regions

One region in Manitoba – Winnipeg Regional Health Authority Research, practice and policy tend to be based in and to reproduce dominant social and institutional assumptions about family/friend caregivers. Using data from a larger study examining the pathways of older home care clients, this paper revisits data on clients' unpaid sources of support to highlight the challenges of dominant understandings of the conditions and sources of unpaid support.

configurations of PARTICIPANTS

HOW WE DID IT

centre around older adults receiving



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non-medical home support, and include the case/care coordinators (CCs), support workers, and where applicable, family carers and private agency supervisors.

STUDY SAMPLE

136*

Clients, caregivers, home care workers, care coordinators and agency supervisors were asked about the clients' sources of unpaid help.

- AND -

Interview field notes and minutes from team discussions contributed to the analysis.

THE HIGHLIGHTS

The unpaid support received by the twelve older adults looked very different than what our mainstream understanding would have us believe. Situations included a number of diverse scenarios including:

 Family members sometimes grappled with physical or mental health challenges limiting their participation in care (sometimes meaning the client is themselves a caregiver or the caregiver is also recipient of home care services).

All of Nova Scotia –

Nova Scotia

Health Authority

- Caregivers facing burnout sought to set boundaries around their participation in care.
- Family members' participation was limited by older adults' reluctance to accept their help.
- Caregivers were unavailable, unreliable, or peripheral.
- Client's unpaid support networks were diffused (widely and thinly spread) without a clearly central or identifiable 'caregiver.'

THE IMPACT

- Existing assumptions about family/friend caregivers' availability and capacity is problematic for practice and policy.
- Existing assumptions and binary views could marginalize caregivers whose situations are more complex.

"Yeah, my daughter's going through some stuff and my son's out in [another province], my older sister well she's just as bad shape as I am pretty much, and my brother lives over in [another city] and he has [specific health condition]."

"Even with myself like when I go there, and I say, 'here I'll do this.' And then she gets upset with me. And she says, 'no, I'll do it, I'll do it.' And just let her be. So I just, instead of getting into an argument...you just [say], 'okay. Let me know if you need help'...And then she says she doesn't want to overburden me either. And I go, 'Mom, it's okay.' Just, but...if I can do it, I'll do it. But if I can't, like I have my own kind of issues too. Like I have (medical condition), so I have a hard time walking."

THE TAKEAWAY

It is important for health care professionals to look at persons providing **informal support more holistically** – beyond simply viewing them as a resource to support aging in place.

Situations of unpaid support persons are varied in terms of physical and mental well-being - along with their willingness and availability to take on such a role. Depending on the situation, particularly when unpaid support workers are more peripheral, these caregivers may be less likely to express caring out of a strong love or bond.

When tasks like care coordination are done by close family caregivers experiencing significant health challenges, this can compound struggle and worry.

Health care professionals should consider how assumptions about unpaid caregivers can inadvertently contribute to, and reinforce, problematic perceptions of caregiver needs.







ABOUT

The Home Care Pathways **Project Overview**

Understanding clients' journeys through provincial home care systems is critical to providing good quality care. "How approaches to care shape the pathways of older adult home care clients" (or "Home Care Pathways") is an interdisciplinary research project being conducted in Nova Scotia and Manitoba. The project draws on different methods and focuses on specific timeframes, in this article's case the approach we considered was around care constellations. The Project's goal is to understand how approaches to care shape client pathways of older adult home care clients with chronic and long-term conditions through the home care systems in the two provinces.

> nsca@msvu.ca homecarepathways.ca







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