



Older People's Experiences of Self-Care, Family/Friend Caregiving, and Formal Home Care

Rachel Barken, PhD
SSHRC Postdoctoral Fellow
Department of Sociology, York University

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Context: Care relationships at home

Older people with chronic health conditions and impairments often receive support from formal home care providers as well as family/friend caregivers. Home care providers, such as personal support workers, nurses, and therapists, typically offer medical and nursing services, and family/friend caregivers might engage in homemaking activities and respond to the emotional needs of people receiving care. Yet, the actual division between home care and family/friend caregiving is often unclear.^{1,2} Add to this older people who are receiving care from others often continue to care for themselves to maintain their own health and well-being. Self-care might include behaviours to prevent health conditions from worsening as well as activities to manage illnesses and impairments.³

Gaps in knowledge

At present, there are gaps in knowledge on the intersections of home care, family/friend caregiving, and self-care. Family/friend caregivers are sometimes poorly integrated into the care experience, and care workers may lack training in accommodating diverse family relationships. Further, care providers know little about the impacts of self-care on experiences and expectations of home care. For example, do clients who do exercises to maintain their health hold different expectations of home care than those who are unable or uninterested in doing exercises?

These gaps in knowledge are problematic because they limit care providers' capacity to respond to diverse family relationships and self-care practices. They can interfere with the provision of person-centered care. Key aspects of person-centered care include sharing power among individuals involved in care relationships; respecting and accommodating clients' needs, perspectives, and interests; and involving clients in decision-making.⁴ It hinges on the development of strong, mutually beneficial relationships between and among home care clients, their family and friends, and formal care providers.⁵

Research questions

This research focused specifically on the perspectives and experiences of older people using home care services. It addressed the following questions:

- 1. How do clients experience the relationship between self-care, family/friend caregiving, and formal home care?*
- 2. How does self-care and family/friend caregiving shape experiences and expectations of home care services?*
- 3. How can knowledge on the relationship between self-care, family/friend caregiving, and formal home care contribute to the development of person-centered care?*

Methods

Qualitative, semi-structured interviews were undertaken with older people using formal home care services and living in the Greater Toronto and Hamilton Area. The interviews explored the support participants received from formal and family/friend care providers; the relationships participants had with care providers, and the ways participants took care of themselves.

The interviews occurred between February and September 2014, and typically took place in participants' homes. They averaged one hour in length. In total, 34 people took part in interviews. The following is a demographic profile of interview participants:

<i>Profile of participants (n=34)</i>	
Age	65-100, average = 81
Gender	26 women, 8 men
Living environment	Own home (19), rental apartment (4), subsidized seniors' housing (5), assisted living/retirement community (4)
Living arrangement	Live alone (21), with family (13)
Home care use	Public home care services (25), pay for home care privately (3), both public and private home care (5)
Health conditions	Varied (people dementia excluded)

Data analysis

A grounded theory methodology was used to analyze the interviews.⁶ This methodology involved developing concepts that were based directly on participants' perspectives and experiences of self-care, family/friend caregiving, and formal home care.

Findings

Participants in this study wanted to find a balance between formal home care, family/friend caregiving, and self-care. With a good balance between systems of care, participants were able to maintain a sense of autonomy even while they experienced chronic health conditions and impairments. Maintaining this sense of autonomy was very important to participants' personal well-being.

The follow three themes show how participants attempted to find a balance between formal home care, family/friend caregiving, and self-care: *Minimizing reliance, developing partnerships, and filling in gaps.*

1. Minimizing reliance: Participants practiced self-care to maintain a sense of independence, and did not want to rely on others for support. Participants wanted to stay as healthy as possible to ensure that their care needs would not increase in the future.

"I do wall push ups and chair sit ups and things like that . . . I eat pretty good . . . and I'll try my darnedest to stay healthy . . . I know, eventually, that I'm going to have to go in a [long-term care] home . . . I'm going to have to really, really try to stay out of there and I think this is how you do that" (Donald, age 70).

Although many participants wanted to be as self-sufficient as possible, some of them turned to formal home care when they needed extra help. If they could afford to do so, some participants used their own money to pay for additional home care services to supplement the publicly funded home care they received. Some participants were concerned about the demands that their care needs placed on family, and did not think it was fair to assume that family would provide the bulk of care.

I have a person that lives here with me. And so I have all the help I need to get from A to B . . . you know, this thing of the family looking after their parents . . . the worst part is that the parent often, I would say, doesn't want to go . . . it's something that should be much more in the hands of the sick person than in the hands of the family (Suzanne, age 80).

2. Developing partnerships: Other participants expressed a sense of *interdependence* between self-care, family/friend caregiving, and formal home care. They sought out and accepted support from others in order to practice self-care in ways that were meaningful to them. With support from others, some participants could stay active, recover from injuries, and prevent health conditions from getting worse.

I go for walks on the sidewalk and there's a nice corridor on the front of this building . . . I always go with somebody, with a caregiver. So that's...that's a help and that way, she can test how I'm doing (Marion, age 89).

Some participants also discussed the mutual support that existed between themselves, family or friends, and formal home care providers. Even though participants needed and accepted support from others, they made decisions about who would help them with what. They had strong networks of support from family, friends, and formal care providers, and this contributed to a sense of empowerment.

The home care worker can do some shopping for you. It's very rare that I ask her to do that but today I forgot to ask anyone [friends] to pick it up. She would have run out and done it. She does whatever I need and even my cleaning lady who I pay, she knows that I have a thing about my place looking really good (Ruth, age 73).

3. Filling in gaps: Although many participants felt that they received good support from formal care providers and from family and friends, there were some participants who had unmet needs for care. These participants felt that the formal home care they received failed to meet their needs. When they could not afford to pay for additional home care, they relied heavily on family. Sometimes, participants felt guilty about the demands that their care needs placed on family.

Well, my daughter does all of it; she does all my shopping; she does all my medication and she's always busy bringing me pads and diapers and toilet paper and Kleenex and she does all she can do . . . she's very worn out. She can be angry, too, but I don't blame her (Rosa, age 93).

While some participants relied heavily on family, there were others who simply did not have family or friends to turn to for assistance. These participants did many things to care for themselves, but their 'self-care' did not lead to a sense of self-sufficiency. They cared for themselves simply because no other support was available to them. In these situations, participants expressed feelings of powerlessness and vulnerability.

Yeah, well if you have to go down to the hospital every day, you want to be clean first. More than one [bath] every two weeks like I've had lately. I'm so tired of sponge bathing I could kill it. But then you've agreed not to have a shower unless there's somebody in the apartment . . . I sponge bath every day but it's still a pain in the b-hind. It takes a lot longer (Angela, age 65).

Implications of findings for person-centered care

Considering the meaning and value that home care clients associate with self-care, family/friend caregiving, and formal home care is important for person-centered care. Many participants' experiences and expectations of formal home care were based on their desire to remain as self-sufficient as possible. Support that recognizes and respects clients' self-sufficiency can contribute to person-centered care.

Empowerment is an important part of person-centered care, and involves supporting individuals' capacity to make meaningful decisions about their lives. Findings from this study suggest that empowerment occurs when home care clients are able to care for themselves in

ways that are personally meaningful, and when care providers support them in making decisions about their care. To promote empowerment, care providers can work alongside home care clients so that they feel well supported, valued, and included in decisions and care activities.

It is also important for care providers to recognize the unique challenges faced by older people who are financially disadvantaged and who have very little support from family and friends. These individuals might need additional support to feel empowered, safe, and secure.

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To learn more about this study, please contact:

Rachel Barken, PhD

SSHRC Postdoctoral Fellow

Department of Sociology, York University

359A York Lanes, 4700 Keele St.

Toronto, ON M3J 1P3

E: rbarken@yorku.ca

T: 416 898-1926

www.rachelbarken.com

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