

# Community Needs Driven Research Network

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## Working with Families

Working with families is an important, but often overlooked, issue in continuing care (CC). The diversity of CC clients in Alberta is reflected in the diversity of the families and their unique journeys supporting a loved one.

### Family Involvement:

There are varying levels of involvement from families. From full-involvement, to informed but only involved when asked, and some are not involved at all. Family participation allows more time for staff to focus on their work and programs with the client as planned. Participants felt that clients with involved families show better attitudes toward recreational activities, more stable moods, were more engaged, had better personal hygiene, and used services more within and external to the facility. This level of involvement allows staff to build trust with families and for families to watch and offer feedback to staff, while also being willing to receive education and information themselves. If trust levels are not met, families can put pressure on staff and cause unnecessary delays on the client's progress. On the other hand, families who are not involved not only impact the client, but also place extra demands on staff, causing them to assume responsibilities outside of their skill and orders.

### How could research be used?

Research could provide evidence and a better understanding of:

1. The impact of family's involvement in client outcomes;
2. Strategies that can positively encourage family participation and family-staff team development; and possibly,
3. Inform the CC sector by giving insight into the expectations of families and their view of their roles in the CC sector.

### What do front-line workers think?

"Some of them say that the staff are their family because they are the only people they see."

"I think we have to really work at including them; I don't think it comes natural to us. So they often play a huge part of that individual's life, but they are just being treated as outsiders coming in, as opposed to part of the care team."

"... but kind of the overarching idea should be that you ask families, you collaborate with families to come up with mutual goals to find out what their values and priorities are."



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### Issues associated with working with families:

Participants also talked about the amount of time and resources devoted to educating families in terms of the disability or aging process of their loved ones. Other factors, such as cultural background, stages of grief, coping strategies, and unrealistic expectations, make this process more complex. Because of this, front-line workers often feel they have to care for not only the client, but also the family. Research needs to be done to explore the dynamics of family-centered practice. Staff feel pressure from society to redefine who their client is and develop strategies to support families in the process. This places an additional burden on family and impacts the quality of life of the client. Research could also help in development of knowledge translation models for families and tools that can provide staff with a framework for communication with families in stressful situations.

### Front-line staff's views:

- “Work with family caregivers, they are so burdened with the information, there’s so much information coming at them that they are scared of the diagnosis, they are scared of what it means, we can provide lots of education, all of us can, but it is how it gets coordinated and repeated in the same way.”
- “We don’t know because it’s also that we get a “Do I want to hear this little piece on the diagnosis” piece, and then at what point can we give them more about long term care then at what point can we introduce end-of-life care.”
- “I’ll talk to families in the hallways, or wherever, and I’ve got them in tears, not meaning to, but it’s because I’m trying to explain to them that this is normal process, they don’t understand it. It’s horrible that families don’t get more education.”
- “What I would like to know about that topic is what families need from us.”
- “The family is kind of the client, you really can’t separate them.”



### Family's knowledge of caregiving:

Participants spoke of growing awareness related to the knowledge that families have as previous caregivers to the client and how knowledge of the client's history and background help them to deal with the management of challenging/responsive behaviours, non-verbal communication strategies, and likes and dislikes. Participants felt the continuing care (CC) sector relied too heavily on academic knowledge and training of staff, and not enough on personal knowledge. Participants felt more time should be spent on practices which involve families as part of the care team.

- “... so family would be a key link to sharing their knowledge of what works with their loved ones and how I can work with them.”
- “...we aren’t giving credit to families with NO education, with NO base knowledge, and they have a vast knowledge that we haven’t respected.”
- “... but have we respected what the knowledge is of the family as a caregiver coming into the care center, or we haven’t because we are nurses and we know it all?”

This issue is strongly related to that of system navigation and transition of care, impacting staff time and efficiency due to the amount of time currently being spent on family education, information, and support.

### What's being done to address this issue?

A research team led by Dr. Wendy Duggleby, University of Alberta, has been funded to look further into the experiences of family caregivers of individuals at the end of life. These caregivers experience many transitions during this time, affecting their physical and mental health. This metasynthesis study will explore what influences these experiences and fill a knowledge gap in end of life care, providing a foundation for future research, policy, and health practices to improve health outcomes.