Connecting People and Community for Living Well

Summary of Learnings

Health Canada Grant

Applied Research Activities

Alberta Health Services Inspiring solutions. Together.

Strategic Clinical Networks™

January 2023

This report has been prepared by Connecting People and Community for Living Well project team.

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Health Canada Grant – Background

During the timeframe of January 2020 through March 2023, five rural community teams (Drumheller, Innisfail, Stony Plain, Three Hills, Westlock) were supported in the Health Canada grant funded portion of the *Connecting People and Community for Living Well* work. With a focus on wellbeing, a series of applied research activities were pursued to increase an understanding of what impacts:

- The *individual wellbeing* of those living in the community affected by dementia (people living with dementia, carers)
- The *collective wellbeing* of the multi-sector community team striving to support those living in their community affected by dementia

Learnings from the applied research activities informed the development of the grants two key deliverables:

1) **Wellbeing Guide**: A resource for multi-sector community teams to measure and monitor The impact of their actions on the wellbeing of those affected by dementia in their community, and of their community team
2) **Competency Framework**: A resource to support understanding the skills, knowledge and behaviors needed to work collaboratively to support those living in the community

This report contains some background information on the applied research activities as well as a summary of the learnings.

Applied Research Activities

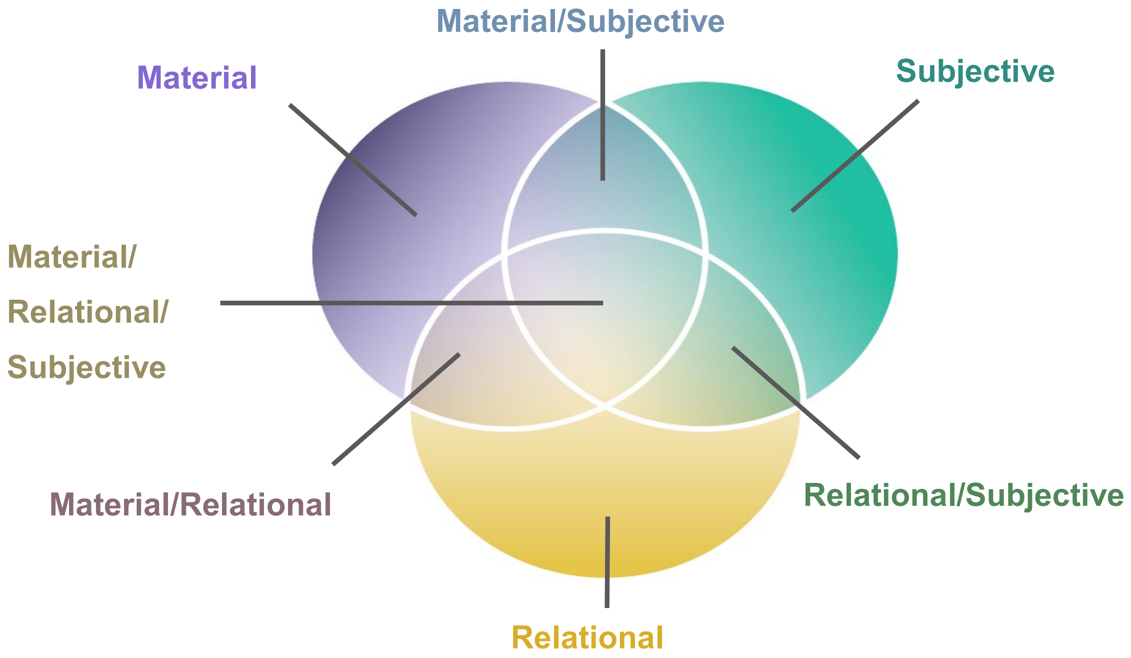
The applied research activities completed in this grant focused on people living in the community with dementia, carers of people living with dementia, and multi-sector community teams striving to support those affected by dementia living in their community. Results represent what they identified as contributing to their wellbeing. The information was obtained through individual interviews (people living with dementia and carers) and focus groups (community teams) conducted between October 2020 and March 2021.

Following a framework analysis approach (Gale et al., 2013) the research team used thematic analysis (Braun & Clarke, 2006) to identify and explore patterns emerging within and across focus groups, and to link the identified themes to wellbeing domains described in the McGregor (2007) framework for wellbeing.

The three domains of wellbeing outlined by McGregor are:

1. Material (what one has)
2. Relational (what one can do through their relationships with others)
3. Subjective (how one feels about what they have, and what they can do with it.)

Additionally, the team found that many contributors to wellbeing that emerged from the interviews and focus groups fell into more than one domain of wellbeing, therefore our model includes areas of overlap.



Learnings from Applied Research

The stories shared by people living with dementia, carers, and members of community teams through the interviews and focus groups respectively have provided a deeper understanding of how to support both individual and collective wellbeing.

Common Themes

The four common themes that people living with dementia, carers and community teams all spoke about, demonstrate that wellbeing - individual and collective - is the result of multiple areas being supported at once. In many ways, it is reflective of the realities of being human. It is not one thing that we associate our wellbeing with, rather it is likely several things. This is true regardless of any diagnosis we have, or any role we play. As you read through the learnings from the applied research work, they may resonate with your own life.

Themes for:

- People with dementia
- Carers
- Collaboratives

Contributing to one's community

Meaningful Relationships

Safe Space

Active in **planning** & **implementing** supports

People Living with Dementia

Quotes from interviews

“I am fighting…[emotional pause] to stay part of… the family and stay part of society [cries]. And not be the sick person or be hidden away.”

"I want to be treated like a normal person”

"I would say, part of it, is our attitude towards it, part of it is the support family or friends that we have a great part of it, it helps because they can encourage you. If you don't have that, people give up and, yeah, people can encourage or discourage.”

“I have adjusted like you have got to. I have… and the thing that has really helped me is that I am not ashamed of this, and neither is my family. But I say that dementia used to be a scary word, and no one talked about it, but I would rather people know that I have dementia rather than I am crazy… you know what I am trying to say."

“…knowing that people care is that someone, you know cares to ask us how we feel, and what are our concerns and stuff like that. My deepest concern is people that have nobody that comes to see them. That is my deepest concern because…boy. I can’t imagine what is that like or being treated you know staff gets frustrated blah, blah, and being treated like not like a nobody, but a burden, right?”

Contributors to the wellbeing of people living with dementia

1) Material Wellbeing contributor: Housing, food, care, clothing needs

People living with dementia have services and resources that help them to:

- Be as independent as possible with tasks of daily living (ex. medication blister packages, phone reminders)
- Feel safe in their community (includes housing, shelter, food, clothing, etc.)

2) Material/subjective contributor: Whole person support - physical, emotional, spiritual, and cognitive

The need to support each individual as a whole person, and not just focus on the diagnosis by:

- Acknowledging/addressing other health concerns.
- Recognizing life transitions (i.e. career/retirement, living arrangements) that have emotional/cognitive impacts.
- Supporting maintaining a sense of who you are now, in the past and into the future.

3) Relational contributor: Care partner and/or family help

People living with dementia are supported to maintain their independence through their relationships with others.

4) Subjective contributor: Confidence in their ability to adapt to the changes related to dementia

People living with dementia demonstrate strength and are able to adapt to the changes and uncertainties that come with the life-changing diagnosis of dementia.

5) Relational/subjective contributors:

Community involvement

- Skills and abilities of people living with dementia are recognized and valued.
- People living with dementia have opportunities to participate in and contribute to their community (i.e. volunteer, community planning.)

Community education to encourage

- Advocacy to combat stigma and to be dementia-friendly
- An increased understanding of dementia, those living with it and their abilities
- A sense of belonging.

Relationships help maintain purpose and meaning.
People living with dementia:

- Feel valued and respected by others.
- Maintain their identity as a person outside of their diagnosis.
- Spend time with other generations (especially children/young people)

6) Material/Relational/Subjective contributors:

Built and natural environments foster inclusion and a sense of safety

- Community spaces are accessible and inclusive as a result of dementia-friendly education and awareness.
- People with dementia feel safe to be themselves and express their thoughts and feelings without fear that they will be judged or left out.
- Information and resources can be obtained in many ways (e.g., online, in newspapers, etc.)

The role of technology
Technology helps people living with dementia to connect with others and improve social engagement/decrease isolation.

Carers

Quotes from Interviews

> **"I’m actually, you know, I’m actually proud of myself because I don’t usually compliment myself, but I’m doing a good job of looking after my mom. But I am tired of doing it [chuckle] you know?”**

“I should eat healthier, I should exercise more, I should, I should, I should, but I would bend over backwards for others but not for myself.”

I: What do you think it would take to change that? To start putting yourself first?

R: “[sighs] I guess in a kind of a crazy way, take someone who valued me and do it with me. Like I can’t do it myself alone, but if I had someone cheering me on and doing it with me, I would do it.”

Contributors to the wellbeing of carers

1) Material **contributors:**

Housing, food, care, clothing needs
Carers have, or have access to housing, food, care and clothes.

Education needs of carers and their community
Carers recognize what types of dementia education they and their communities need.

2) Material/subjective contributor:

Carers recognize and believe in their own abilities
Carers feel confident in their ability to provide ongoing support to their person living with dementia.

3) Subjective contributor:

Maintaining a sense of who you are through purpose and meaning
Carers find purpose and meaning from:

- Being a primary caregiver.
- Their personal interests.
- Roles within their community.
- Continuing activities unrelated to caring in their community and family.

4) Material/relational contributor:

Choice in supports/services and how they are delivered
Carers have choices when it comes to supports. They are part of determining the type of service and how/when it is delivered.

5) Material/relational/subjective contributor:

Safe space
Opportunity and time to be able to share experiences, seek advice and feel supported.

6) Relational/subjective contributor:

Emotional and psychological needs
Carers need to:

- Have someone with whom they can share their feelings.
- Talk about how they are managing.
- Be treated with respect, and have their independence supported.

A key aspect of addressing emotional needs is the timely diagnosis of dementia for their loved one. Diagnosis supports carers in:

- Understanding their relationship and personal changes, decreasing their frustration.
- Having the opportunity to plan, share feelings and find support with the person with dementia.

7) Relational contributor:

Supportive relationships
Relationships are key in carer support. Carers need:

- To be able to identify relationships that are helpful, and which ones are stressful.
- Opportunities to be involved in activities where relationships are positive and supportive.

Positive relationships with healthcare

- Carers are seen as a key part in determining what and how care is provided to the person living with dementia.
- Healthcare providers treat the carer with respect and involve them in all aspects of care.

Technology supporting connections

- Having and knowing how to use technology can help carers keep existing relationships and build new ones.

Community Teams

Quotes from focus groups

“I think that that’s important to acknowledge… that coalitions can be fantastic, energetic, and committed people. But oftentimes…we are having to do this off the side of the desk. And so the times where we’ve been able to really capitalize on this coalition is when we actually have a little tiny bit of [laughter] dedicated funding to have a staff really drive things forward. And I think that’s important… coalitions…benefit from people’s passion, but you can’t deny that it does need some financial resource to go towards a dedicated staff person.”

“Well, we needed to do that also to see what each organization could bring to the table. And then you have a much better understanding of where those barriers lie within each of our organizations and how far we can push that and don't get me wrong, we've pushed that far. But again, we share that responsibility, which is good.”

“I think it always goes best when you have your supervisor’s support. You know, if they're giving you time to attend and do things that makes it much easier rather than trying to do it off the side of your desk on top of everything else, that spreads everyone thin.”

Contributors to the wellbeing of community teams

1) Material contributor:

Time and dedicated resources to actively participate in the ongoing work

- Collaboratives have the time and resources to carry out the planned activities of the collaborative.
- Members are supported by their leadership to participate in the collaborative.

2) Material/subjective contributors:

Policy Priority

- Local and provincial governments see collaborative work as important.

Communication

- There are formal ways for collaborative members to share information with fellow members

3) Relational contributor:

Dynamics between members

- Members contribute equally to the decision-making processes

4) Relational/subjective contributor:

Teamwork and relationships are foundational to achieving collaborative goals

- Partnerships and relationships in the collaborative and in the community are key to identifying goals and making progress.

5) Subjective contributors:

Shared vision and purpose

- Each member understands the purpose of the collaborative.
- The collaborative has processes to help them achieve their goals.

Outcome-focused work
Collaborative members:

- Are action oriented.
- Want to impact community in a meaningful way.
- See progress through achieving goals.
- Have ways to illustrate the work they are doing and results they are achieving

6) Material/Relational/Subjective contributors:

Membership

- Membership is diverse.
- Members are clear on what their role is.

Identifying and meeting learning needs

- Collaboratives identify where education can support them and look for ways to receive that education**.**

Actively seek input from those with lived experience (people living with dementia, carers)

- Collaboratives use a number of ways to involve those with lived experience.