

# Achieving holistic, quality-of-life focused care: description of a Compassion Care Community initiative in Canada

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# **Summary**

The compassionate community movement as both a public health approach and a social model of care for various life stages is gaining traction in Canada and elsewhere. One example is the Windsor-Essex Compassion Care Community (WECCC), an evidence-based model and set of tools to improve the quality of life, health and wellness of vulnerable and aging populations by identifying and addressing upstream and downstream social and other risks to physical and mental health. This paper presents findings from the WECCC pilot evaluation. The WECCC initiative provided one-on-one volunteer-supported quality of life assessment, resource navigation and goals support program (Catalyzing Community Connections). This was augmented with public education sessions on social connection and loneliness (Importance of Being Connected) for the broader population. The RE-AIM framework was used to frame evaluation of WECCC through the first 4 years. Questionnaires were used to evaluate participant outcomes related to implementation and effectiveness. Interviews and focus groups were completed to understand impacts. From 2017 to 2020, WECCC has engaged over 2,500 individuals, 65 organizations and 400 volunteers combined in both programs. Nearly all (82% to 95%) participants reported positive changes to health, quality of life and/or social connections. This developmental phase of a compassionate community initiative has allowed piloting of an evaluation framework focusing on reach, adoption, implementation and early signals of effectiveness and maintenance. This demonstration provides information on feasibility, acceptability and potential impacts of this type of over-arching community initiative.

### Lay summary

The compassionate communities movement is a social and holistic approach to care that engages community members in caring for others. The movement is growing around the world. The philosophy is that all citizens benefit from participating in care for others who are aging, disabled, nearing end-of-life or struggling with determinants of health. The Windsor-Essex Compassion Care Community (WECCC) is a Canadian example of this model. WECCC seeks to improve the health of people at any stage of life by helping them to identify their life needs and goals and providing them support to meet them. The program has two core components: one-on-one volunteer-support for person-directed goals and navigation (Catalyzing Community Connections) and public education sessions about loneliness and social connection (Importance of Being Connected). Evaluation is a routine part of program delivery with questionnaires, interviews and focus groups used to understand the program's outcomes. From 2017 to 2020, WECCC has worked with over 2,500 individuals, 65 organizations and 400 volunteers. Satisfaction with the program is very high (95%). Nearly all participants reported positive changes to their quality of life (82%) and social connections (95%). Although pilot results are favorable, continued evaluation and stronger research designs are needed to comprehensively evaluate the WECCC program over time and to support growth and spread of the model.

Keywords: health promotion, volunteers, social isolation, quality of life, population surveillance

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### **BACKGROUND**

As people live longer, the proportion of the population with chronic diseases, disabilities, care dependency and end-of-life support needs is increasing (The National Seniors Council, 2014; Eckerblad et al., 2015). As the focus of care shifts from disease cure and management to maximizing quality of life and well-being, social care and holistic support are increasingly recognized as societal priorities to addressing aging, disability, structural inequality, death and dying. Social factors play a significant role in well-being, as they are associated with risks of chronic disease, high-cost health care use and early mortality (Holt-Lunstad et al., 2010). To achieve the World Health Organization's model of healthy aging, health and social care systems are needed that bridge physical, mental, social and spiritual care (World Health Organization, 2016, 2021). Approaches to prevent and mitigate the impacts of isolation, functional decline and care dependency are critical to improving public health responses to population aging.

Healthcare systems are structurally challenged to respond well to people with complex health and social needs (Tinetti et al., 2012; Lewis, 2015; Roy et al., 2015; Wilson et al., 2016). People living with multiple comorbidities, those who are nearing end of life, aging but socially isolated or vulnerable through structural inequities, need care that is tailored to their unique challenges, but receive care within systems that are not coordinated or person-centred (Kuluski et al., 2016; Lyons, 2016). Vulnerable sub-populations are disproportionately affected by increasingly overburdened healthcare resources, sub-optimal efficiency in community care management, and a high level of variability of access and quality across primary care, home care, community support, and hospice sectors (Doran et al., 2007; Laporte et al., 2007; Polisena et al., 2010; Sinnott et al., 2013; Moin et al., 2018).

The 1986 landmark "Ottawa Charter for Health Promotion Conference" recognized that the mechanisms to achieve healthy societies include healthy public policy, supportive environments, community action, development of personal skills and reorienting health services (International Conference on Health Promotion, 1986). Care models that respond to peoples' goals and values can help build resilience and increase capacity by marshalling networks of support including family, friends, neighbourhoods and schools. Models of health and social care integration that embody these principles are emerging and showing benefits for both individuals and health care systems (Sallnow et al., 2016; Abel, 2018; Abel et al., 2018a, 2018b)). For example, a UK compassionate community initiative that integrates personalized care planning in primary care alongside proactive community development demonstrated a 40% reduction in unplanned hospital admissions (Abel et al., 2018a, 2018b).

Since the introduction of public health approaches to palliative care (Kellehear, 1999, 2005), the Compassionate Cities model has gained international traction as a social model of care for those living with serious illness, caregiving, dying and grieving by de-professionalizing and de-medicalizing end-oflife care, returning it to the community, and building up social capital (Abel, 2018; Abel et al., 2018a, 2018b; Hassan, 2015; Librada Flores, 2018; Aoun et al., 2020; Pesut et al., 2020). While compassionate community approaches to mobilize community members or volunteers to create supportive networks have focused mainly on end-of-life populations (Sallnow et al., 2016; Aoun et al., 2020; Pesut et al., 2020), their applicability to other life stages and situations has been recognized (Abel et al., 2018a, 2018b; Tziraki et al., 2020).

A new conceptual model, the (Health Impact Change Model) model was developed to guide the implementation and evaluation of a Canadian compassionate community intervention (Pfaff et al., 2020) that extends these principles beyond endof-life to address issues of belonging and inclusion across the lifespan for people whose age, health or social circumstances hinder their equitable participation in society. Over the past 4 years, a coalition of community leaders and organizations have been working together voluntarily to operationalize implementation of the (Health Impact Change Model) model in the city of Windsor and the seven townships of Essex County in southwestern Ontario. The Windsor Essex Compassion Care Community (WECCC) was launched as a community co-designed and participatory initiative to measurably improve population health, wellness and quality of life; develop innovative approaches to address social isolation and reduce inequities amongst traditionally underserved groups.

In this paper, we describe the components of the WECCC initiative, preliminary evaluation of the experience and impacts among participants and lessons learned regarding feasibility, spread and evaluation.

#### **METHODS**

### Program history, goals and description

WECCC is an evidence-based model and set of tools to improve the quality of life, health and wellness of vulnerable, aging and other populations by identifying upstream and downstream risks to physical, mental and social health. WECCC started as a grassroots initiative supported by the Hospice of Windsor Essex and led by a hired program director who engaged community partners in the development process. The program theory is based on personalized assessment of quality-of-life opportunities, outcomes and needs,

goal and action planning, navigation support for community-based connection, and the iterative use of population-level outcomes to translate knowledge and forge new community development efforts that build more caring and resilient neighbourhoods (see Supplementary File 1 for program components).

# Stage 1 development—Catalyzing Community Connection (CCC)

The initial community priority was to improve community support networks for individuals and their caregivers that address personalized goals and unmet health and social needs. Because health equity is an important goal of WECCC, the original program was designed for people who need one-on-one support. This includes those with more complex needs such as living at home with serious illness, frailty or disability, and people with low income, precarious housing or mental health issues. However, the CCC program itself is open to everyone—having specific risks is not a requirement for entry and people can self-refer.

At program initiation, trained staff and volunteers provide one-to-one virtual, phone or in-home support to people/families. All new registrants receive support in self-rating their quality of life, setting goals, navigating community resources, joining new programs or activities, meeting people with shared interests and helping others. After approximately three to six months of support, participants redo their quality-of-life self-reports and graduate to check-in support. Follow-up is personalized to each individual's needs, interests and preferences. On-going support may include reassurance and friendly visiting/phone calls, repeated measures tracking, review of goals/ progression of goal achievement and new actions, opportunities to participate in health and wellness modules (e.g., reminiscence therapy, communication, self-management, advance care planning), connection events and/or support groups (grief, caregiver) and giving back to community (random acts of kindness, offers of time and talent to others).

The program has been tested for suitability with specific populations including seniors, frail elderly, people with chronic disease, serious illness, at the end of life, with mental health conditions, disabilities, living in poverty or experiencing homelessness, migrant workers, LGBTQ2+ groups and family members caring for these people. The model was initially developed in community and health care organizations such as hospice, home and community care, family medicine clinics and mental health organizations. These organizations were involved both independently and as part of an "all of community" approach.

# Stage 2 development—the importance of being connected (IBC)

In addition to health equity, a second goal of WECCC was to advance population level health promotion and preventative care. As a result of early experiences with the CCC program, it was realized that many community residents who are at risk for disease and premature mortality can be empowered to reduce risk factors through heightened awareness and better information. Thus, the community quickly recognized that elements of the CCC model could be scaled through tailored public education in group settings. Self-assessment tools and general resources were introduced to enable participants to identify and connect themselves to supports and activities to improve their well-being, and to be aware and more actively involved in helping others. Based on the earlier experiences of engaging broadly with the community and hearing the factors that influence their well-being, "The Importance of Being Connected (IBC)" sessions focus on the effects of social isolation and loneliness. IBC is a scheduled event to engage the public and people in groups to learn about the risks and etiology of loneliness and strategies to reduce it. Trained facilitators engage participants to plan their life to live well and to use their compassionate spirit to contribute to the wellness of their family, neighbours and communities. Participants complete activities and learn where they can get help when they need it. They self-rate their quality of life and receive personalized results, including tools and tips.

Participants who complete a quality-of-life survey and provide consent for follow-up are screened in terms of quality-of-life risks. High-risk participants are identified and are proactively offered access to the CCC program, should the person wish to receive extra support for goal setting, action planning and community navigation.

# Research and program evaluation

Research and program evaluation is embedded in program operations and includes both quantitative and qualitative research methods. All participants are invited to indicate their willingness to participate in research and evaluation but are also informed that it is not a requirement of engagement in WECCC programming. Ongoing informed consent is gathered at each data collection point. (Research Ethics Board at the University of Windsor) A volunteer team of researchers continue to refine the on-going research, program evaluation and continuous quality improvement methodologies that are built into program delivery.

### Evaluation framework

While the program evolution was aligned to developmental evaluation in which feedback mechanisms embedded in implementation were continually used to improve the program (Patton, 2010), we present the program outcomes at this stage according to the RE-AIM framework. The RE-AIM framework is an evaluation tool designed to assess the impact of public health or population-based programs or policies and has also been used in clinical and community-based interventions (Glasgow and Estabrooks, 2018). The intent of the framework is to improve the sustainable adoption and implementation of effective, generalizable, evidence-based interventions. We used RE-AIM because the elements of this program are meant to be customizable and implementable in any community across a variety of settings and populations, and would-be adopters from other communities desired evaluation information on issues that would inform their plans such as reach and adoption. There are five evaluation dimensions in RE-AIM (reach [individual level], effectiveness, adoption [setting level], implementation, and maintenance) (www.re-aim.org/about/ what-is-re-aim/, last accessed 6 October 2021).

#### Data collection and measures

Satisfaction, experience and effect on quality of life.

CCC participants complete a survey at 'graduation' to check-in support. Our target for program quality is that 85% or more of CCC participants will be satisfied with their experience and would recommend CCC to others. Participants also complete the "Neighbours Survey" on interests, quality of life, community connections and aspirations every 6 to 12 months (https://www.healthcommons.ca/project/neighbours, accessed 6 October 2021). The target for program effectiveness is that 75% or more of CCC participants will:

- 1. Feel that because of CCC, their life is better than before
- 2. Have developed knowledge, skills and connections to improve quality of life, demonstrated by feeling:
  - a. Better able to deal with challenges
  - Better supported by community, friends and family
  - c. More confident in getting the help they need
  - d. More confident in plans for future care

In the IBC program, clients complete a survey immediately after the session, asking about the relevance and usefulness of the education. A second survey is administered 6 months later as part of the check in call. These surveys assess relevance of the program, extent of new

skills and knowledge acquired and whether and how the participant has applied the new knowledge through life changes (see Supplementary File 2 for surveys).

In-depth qualitative evaluation.

Individual interviews and focus groups were conducted to explore impacts of both program streams, from 16 CCC and 12 IBC participants. These involved clients, staff, volunteers, providers and community partners. Structured interview guides were used to elicit information on aspects of the programs that were considered helpful and why, as well as barriers and opportunities for improvement. Interviews and focus groups were audio-taped and transcribed verbatim.

## Data analysis

Data from surveys and program records were analyzed descriptively using counts and proportions. Mean differences in Neighbours Survey (quality of life outcome) measures were calculated from baseline to the first follow-up and survey retake. Paired t-test was used to determine statistical significance of changes. A p-value of less than 0.05 (two-sided) was considered statistically significant. Qualitative data were analyzed using inductive and deductive procedures by a nursing research team at the University of Windsor. Data coding was completed by hand, supported by NVivo software. Data abstraction to spreadsheets, templating and creating matrices were used to compare, re-organize and revise the data iteratively (Thorne, 2008; Miles et al., 2014). Content analysis (Hsieh and Shannon, 2005) and other descriptive and interpretive procedures (Crabtree and Miller, 1992; Thorne, 2008) were applied to generate findings to assess program impact, and to understand program implementation and areas for improvement and new development.

### RESULTS—CCC PROGRAM

#### Reach

Between 2017 and 2020, the CCC program served an average of 15–20 new referrals per month (with lower numbers in 2020 because of the COVID-19 pandemic). As of December 2020, the CCC program was carrying 504 members on its caseload, with an average of 93 individuals per month working through intake, and 404 per month receiving check-in support. Approximately two-thirds (63%) of participants were seniors and others were adults with disabilities. Most (72%) are female. The profile has been relatively consistent from year to year.

### Adoption

Over the period 2017–2020, the CCC project team was located at Hospice Windsor Essex, and 42% of

**Table 1:** Referral sources and numbers of participants in the Catalyzing Community Connections program from 2017 to 2020

Referral source	Number of settings or organizations	Number of participants	
Hospice Palliative Care Sector—community hospice	1	214	
Emergency services sector	1	12	
Hospital sector	2	33	
Primary care sector	3	13	
Home and community care sector	3	40	
Mental health sector	2	8	
Community sector	4	9	
Self-referral			
Public Education (IBC) events: risk screening	Not available	68	
Self/family/volunteer		61	
Unknown		59	

members came from the hospice palliative care sector. Nevertheless, CCC has created partnerships across multiple health service and community sectors, including emergency services, hospital, primary care, home and community sectors and mental health sectors (Table 1). Beginning in Fall 2020, the CCC program began shifting from a referral-based program located at a community hospice to a model of embedded referrals and adoption with a wider range of community partner agencies, sharing student and volunteer resources with additional partner agencies. This shift was intended to enable growth and spread of the model to new populations, settings and geographies while reducing barriers to adoption.

### **Implementation**

As adoption of the CCC program is distributed across different agencies and geographies, and to promote fidelity of the program, front-line coordinator positions employed by sponsor organizations are also given responsibility for student and volunteer supervision servicing community partners. The CCC Coordinator provides weekly supervision meetings and oversees program delivery and quality. Volunteers and students undergo training in Community Connection Intake and Check-in. They are assigned by the CCC Coordinator to various adopter agency partners under the terms of an agreement worked out with them. Adopter agencies also participate in identifying and recruiting new participants and supervising student direct patient encounters where needed. Qualitative data reveal positive volunteer perspectives of the usefulness of the training and education. The training was described as "gold standard" and there were no recommendations for improvement expressed by volunteers:

The training...was really informative because it gave me a better concept of what the program was all about and helping them get more connected... to other help within the community or other people who are similar and looking for connection... I want to make sure I focused on them and also the idea that you shouldn't be jumping into to help fix things for them, that really the program is about helping them make connections to improve their lives... (volunteer).

The analysis of qualitative interviews also revealed that successful implementation processes involve: (i) empowering participants to set and act on personal goals, (ii) taking time to address needs, goals, preferences and follow-up and (iii) advocating for programs and services that fill the gaps in complex health and social care. The following is an exemplar quote from a CCC program coordinator:

We draw on different parts of the program for different people...it's different parts that help make the difference. I think the most important part of it is the establishing of SMART goals. Those provide direction and they also help actually motivate the clients to achieve the goal that they have identified...We're having a conversation with the client at a pace that's appropriate to them with intentions of building a report with client and in doing so, they begin opening up about things that they want to work on, difficulties that they're having that they often have not shared with other people or they have shared it and it hasn't really been addressed...

### Participant satisfaction and experience

Since 2017, 174 CCC program participants completed surveys, demonstrating that quality targets were met (Table 2). In 2020 with the pandemic, some measures decreased slightly but were near target.

### Participant self-rated quality of life

At the start of CCC participation and every 6 months thereafter, the 'Neighbours Survey' is routinely collected, using validated instruments to measure self-rated health (including functional limitations); mental health; personal well-being; social isolation, loneliness and social participation; and use of wellness supports/health system resources.

**Table 2:** Satisfaction and experience survey responses from the 174 Creating Community Connections (CCC) participants

Quality measure	2017– 2019 ( <i>n</i> = 100)	2020 ( <i>n</i> = 74)	Target
Satisfaction with experience Would recommend CCC to others	92% 97%	95% 99%	Exceeded target
Life is better than before	82%	70%	Did not meet target
Better able to deal with challenges	89%	79%	Met target
Feel better supported by community, friends and family	95%	73%	Borderline target
Feel confident in getting the help they need	94%	83%	Met target
Feel confident in plans for future care	93%	74%	Borderline target
% participants who felt the program met or exceeded their expectations <sup>a</sup>		96% (55% exceeded; 41% met)	Met target
% participants who think the program should continue in the community <sup>a</sup>		100%	Met target

<sup>&</sup>lt;sup>a</sup>New indicator added in 2020.

# Community partner and volunteer satisfaction and experience

Because the CCC model is highly dependent on the engagement of both community partners and volunteers, we track volunteer and community partner experience as another program quality measure. In 2020, 39 survey responses were collected (30% from partner agencies; 50% from community volunteers and 10% from student volunteers). Eighty-seven percent of respondents were satisfied or very satisfied with the experience with the CCC program and 100% would recommend involvement with CCC to others in the community. Ninety-five percent of respondents felt their involvement met or exceeded their expectations, and 87% felt people in the community are being better served by families, neighbours and community groups as a result of the program. Eighty-three percent felt that people served by the program were better able to deal with challenges and get the help they need, and 85% felt people in the community have more opportunities to share their time and talents to help others. Seventy-nine percent indicated that their involvement with the CCC program has caused them to think differently about how to serve people in the community.

Our qualitative data suggest that among high-risk populations, the program can act as a safety net to prevent members from falling through the cracks of the formal care system because of vulnerabilities such as low income, physical and mental disability, and housing insecurity. Participants perceived positive impacts in mental health, appropriate use of emergency medical services, housing support, and chronic disease management.

I have this [client] she's on hemodialysis...and had a fire in her condo... Her son passed away and the grandson became disconnected. She...was missing dialysis a lot, was going to the ER with shortness of breath...[Lack of] a constant ride to dialysis was the reason she was missing it, plus she was suffering some depression... It took a lot of coordination, but we were able to get her rides. I was able to get her providers to start early, to get her ready for dialysis, get her on and off transport...WECCC dug deeper and was able to connect with the social worker and found funding to get this ride and now her dialysis times have been changed... She has been getting support for her depression in dealing with her loss and I think it's been a success. (Coordinator from a community partner organization)

# Pre- and post-participant self-rated quality of life

Based on the average group outcomes for the 55 clients who completed both baseline surveys and post surveys at graduation, statistically significant positive impacts/ improvements were demonstrated in mental health, ability to do usual activities, perceived loneliness, size of personal network, wellness support and perceived future security (Table 3). Personal well-being and number of social contacts also increased but the changes were not statistically significant.

### Maintenance

As we collect additional records and data from 6- and 12-month check-ins, we will be able to assess the medium-term effects of the CCC program on satisfaction, social connectedness and quality of life. For many vulnerable people, community connection is a lifelong journey and we expect to see fluctuation—both improvement and decline—in quality of life outcomes for participants, particularly for those who experience declining health. Nevertheless, our hope is that we will

**Table 3:** Scores on quality-of-life measures at baseline and 6-month follow-up among Creating Community Connections (CCC) participants and Importance of Being Connected (IBC) participants

	Baseline mean	6-month Follow-up mean	Mean difference (95% confidence interval)	p value
CCC Program				
Mental health (0-4)	1.7	2.2	0.5 (0.1, 0.9)	0.007
Ability to do usual activities (0-4) <sup>a</sup>	1.9	1.4	-0.5 (-0.8, 0.2)	0.0004
Perceived loneliness (1-3) <sup>a</sup>	2.2	1.8	-0.4 (-0.7, 0.3)	0.007
Size of personal network (total number spouse/partner, friends, children)	5.0	9.4	4.4 (1.5, 7.4)	0.005
Wellness support (0–10)	2.9	5.5	2.6 (1.6, 3.6)	< 0.001
Future security (0–10)	5.6	6.8	1.1 (0.1, 2.2)	0.04
Overall personal well-being (0-100)	55.7	60.9	5.2 (-0.8. 11.3)	0.09
IBC Program				
Ability to do usual activities (0-4) <sup>a</sup>	0.6	0.5	-0.1 (-0.1, -0.3)	0.04
Perceived loneliness (1-3) <sup>a</sup>	1.6	1.4	-0.2 (-0.3, -0.1)	< 0.001
Progress achieving goals <sup>a</sup>	1.7	1.5	-0.2 (-0.3, -0.1)	< 0.001
Number of social contacts (0–28, never to daily)	14.6	18.9	4.2 (3.1, 5.3)	<0.001
Wellness support (0–10)	2.8	4.3	1.5 (1.0, 1.9)	< 0.001
Use of emergency department in last 12 months (number of times) <sup>a</sup>	0.8	0.4	-0.4 (-0.7, -0.02)	0.04
Overnight stay in hospital in last 12 months (number of times) <sup>a</sup>	0.5	0.1	-0.4 (-0.9, -0.1)	0.02

<sup>&</sup>lt;sup>a</sup>Decrease in score represents an improvement.

see some improvement in community and personal connections, with smaller fluctuations on these measures over time as support systems becomes more connected, responsive and personalized.

### RESULTS-IBC PROGRAM

#### Reach

In total, 2,010 residents in Windsor and Essex County (total population approximately 400,000) participated in public education on loneliness and social connection, which exceeded the target of 1500 between 2018 and 2020. The number of participants grew from 36 in 2017 to 635 and 1000+ in 2018 and 2019, respectively. Due to the inability to provide face-to-face programming during COVID-19 in 2020, the number of new participants declined to 323. Approximately 85% of participants have been female and 60% were seniors. Others engaged are caregivers, adults with disabilities or mental health conditions. Canadian newcomers and international university students. Most participants reported themselves as being in good health, and about 5% were identified through screening as experiencing significant physical, mental, or social life challenges.

### Adoption

Since 2017, this program has been offered 379 times, in 147 locations (including virtually), providing over 800 h of public awareness raising and education. IBC workshops were offered in seniors and public housing buildings, community health and wellness centres, hospice wellness programs and in faith-based communities. One-third of locations offered repeat education workshops.

### Implementation

Adaptations were made to the program based on community and participant feedback. IBC was originally offered as a 4-session program called "Life and Living Well," which offered the same course overview along with more in-depth education and assistance with goal setting and community navigation. IBC facilitators were part-time employees of WECCC whose role on the team was dedicated to running the IBC program. Ninety-nine percent of all IBC workshops were conducted by paid WECCC staff. The IBC facilitator recruited students and volunteers to assist at the sessions and supervised their training. This provided a high degree of consistency throughout the

program. This program was scaled back in its second year to improve access and uptake. While the core workshop materials remain the same, the program provides a degree of flexibility to customize delivery based on group preferences (for example, reducing the length of the session) and tailoring key messages and follow-up based on the unique circumstances of each target audience. People who require additional assistance are connected to 1:1 support for follow-up where needed.

#### Effectiveness

Data that capture the quality and effectiveness of the IBC program are routinely collected from participants, community partners, students and community volunteers.

# IBC participant experience: workshop feedback survey

Two quality measures were assessed, namely, the percentage of positive participant ratings at the end of the session for (i) satisfaction: new knowledge and skills acquired and (ii) relevance of education to participant needs. Approximately 1,000 feedback forms were received (50% response rate). Consistently each year, 85% of participants indicated that the learning was relevant to their needs, important for personal learning and were appropriately presented and 95% reported new knowledge and skills. Representative survey openended comments included "astonished loneliness is so bad for us," "I need to be more aware of my neighbours" and "this presentation was just what I was needing in my life".

Qualitative in-depth impact interviews confirmed findings: "I was very impressed with...the presentations that...really showed you the benefits of people being connected. The data that they showed on what makes people happy was so spot on that you really felt this was definitely something that was a huge need." (IBC participant). The qualitative data also suggest that the program is having positive impacts on participant mental health by decreasing social isolation.

As one example, after attending an IBC event, a participant indicated that she was volunteering at a local fair because of what she learned.

"What I learned has changed my life. I'm listening to what you told me!" (IBC participant)

The IBC program processes involve building awareness of the negative health effects of social isolation and the intentional and persistent reaching out among members in relational and practical support. The following two exemplar quotes support this finding:

"One of our knitting ladies brought her neighbour and really she was such a depressed woman all by herself in her home...She's got that connected feeling now and she's even said to me, 'it just gives me a reason now to get up and get dressed and I'm going out [now] two days a week'." (IBC volunteer).

"A couple of very isolated people came to an event...and from that, they developed a relationship where they look out for each other...I've gotten involved in the coaching group and I've seen the same sort of thing happened where people are connected through life experiences...and the [new] friends really sustain them." (IBC volunteer and participant)

# Pre- and post-participant self-rated quality of life

Statistically significant improvements were reported at the six-month follow-up among the 227 participants for health today, ability to do usual activities, progress achieving goals, perceived loneliness, number of social contacts, wellness support, use of emergency department and overnight stays in hospital (Table 3). Not surprisingly, since most post surveys were collected in 2020 during the COVID pandemic, this group reported decreased frequency of community participation—but without this affecting loneliness or number of social contacts.

### Maintenance

Since 2019, 1,945 check-in calls were attempted with 671 direct conversations with participants. At our 6-month check-in calls, about 75% of these respondents indicated that they had made changes in their personal lives, and/or they have been more proactive in reaching out to others since attending the class. The same proportion reported making progress in achieving goals.

#### DISCUSSION

We evaluated the developmental phases of the CCC and IBC programs, especially the effects on social connections to support quality of life needs. Through iterative stages of development from 2017 to 2020, this initiative engaged over 2,500 individuals, 65 organizations and 400 volunteers, demonstrating that communities are willing and able to mobilize and collaborate to improve connection and population well-being. Efforts to understand how this organized but flexible community-based health program and data platform can support population health is on-going.

Evidence is mounting for the benefits of community development for improving the quality of life for people with advanced illness and near the end of life (Abel *et al.*, 2013; Sallnow *et al.*, 2016; Librada Flores *et al.*,

2018). We employed education, goal setting and navigation, and 'giving back' through volunteerism and community organization partnerships, processes drawn from public health approaches to disease and end-oflife care (Sallnow et al., 2016) The WECCC model was tailored to focus on determinants of health, social participation and well-being across the lifespan, with the value of the connections and activities being defined by each individual participant. This individual values-based lens was likely key to WECCC's ability to reach and be accepted by a range of populations including university students, Canadian newcomers, and older adults. At the individual level, people participate in supporting their own health and wellness via their own unique, personalized, community-based care network, leveraging relationships and wellness activities as well as informal and formal care providers, and accounting for the aspirations and trade-offs that are most important to them. The model also appears to enable health providers, community groups and communities to coordinate with each other and take collective responsibility for group health, wellness and equity outcomes. By mapping assets, identifying risks and making patterns of care and health more visible across neighbourhoods and care settings, substantial re-organization of health and social services and supports is expected. In this way, program outcomes can be used to reinforce common goals that "span levels of influence" across individuals, organizations, and the community (King, 2015).

A key learning is the need to be adaptable to different populations, while remaining consistent with foundational principles through a public health approach. A simple 'light touch' public education initiative on social isolation and connections was more feasible and impactful than expected. The first, more intensive CCC program was accessed by a smaller number of participants but demonstrated positive impacts in terms of ability to reach and engage people who were highly marginalized, isolated and falling through the cracks.

Health systems routinely collect and track data aimed at preventing or responding to diseases and symptoms, injuries, deaths, disasters and health-related behavioural risks. Currently, surveillance data related to social risks are not systematically collected and disseminated for actionable responses (Adler and Stead, 2015; Zhu et al., 2019). The WECCC model has potential to address this gap and holds promise for aligning to the Institute for Healthcare Improvement's Triple Aim framework. Three key elements can be highlighted: creating the right foundation for population management, managing services at scale for the population and establishing a learning system to drive and sustain the work over time (Whittington et al., 2015).

The current evaluation has informed the technical and data infrastructure needed for future growth. To

advance the learning health system approach, individual-level outcome data that are aggregated at various levels will be linked to a dashboard tool for display of real-time monitoring of the population by spring 2022. WECCC is working towards creation of a community-wide data platform where quality of life outcome and social connection data can be linked to routinely collected population-based illness-oriented data, as a key to a enabling a learning health system. Such system-wide linked data would lead to better understanding of the relationships amongst different social factors, the link to health, well-being and mortality outcomes, and the impact and value of community initiatives (Hu et al., 2017; Fisher et al., 2020). In the absence of specific research and evaluation funding to achieve linkage at this stage, WECCC has begun to collect self-reported health care utilization information. The challenges of rigorously collecting both qualitative and quantitative information for evaluation through utilization of trained volunteers are not insignificant. However, our project confirmed previous findings that volunteers from the community can successfully enact roles of assessing the needs and goals of people in the community, being the "eyes and ears" of health care providers in the community and being connectors to care (Woldie et al., 2018; Dolovich et al., 2020; Gaber et al., 2020; Pesut et al., 2020).

Strengths of this evaluation study include flexibility in tracking program development and implementation, the engagement of multiple perspectives and stakeholders (clients, family members, volunteers and cross-sectoral organizations) and the embedding of evaluation within program participation. The RE-AIM framework was helpful to digest the data to date; however, evidence of the program's impact on quality of life and healthcare system outcomes is only beginning. We did not have a control comparison group, and the self-reported data may be subject to biases such as social desirability. Future research will be needed to establish rigorous evidence of effectiveness at individual and population levels and determine the key factors that will support wider implementation. Usual research paradigms that test static interventions in homogeneous groups of individuals may be difficult to apply. Frameworks from implementation science and hybrid effectiveness-implementation research approaches that illuminate context specific enablers and barriers to success (Curran et al., 2012) will help move this field forward.

## **CONCLUSION**

It is feasible to engage volunteers, mobilize communities, collect information on quality of life and social health outcomes and measure change over time that is linkable

to personal and community social environments. Built-in routine measurement of outcomes and real-time feedback loops can drive quality improvement. Broad coalitions of community partners can be engaged to nudge wider health improvement efforts. The process demonstrated that multiple versions of an intervention that includes core processes of education, screening, assessment, care planning, goal setting, navigation, ongoing monitoring and capacity development are needed for population health initiatives. Routine collection of evaluation data over the long term will be required to determine whether and how this program can achieve meaningful change in population health and well-being and to maintain gains. This developmental phase of a compassionate community initiative demonstrated the critical elements of the approach and evaluation going forward.

# **Supplementary Material**

Supplementary material is available at *Health Promotion International* online.

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### **Ethical Statement**

The research adheres to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Panel on Research Ethics, 2018) and was cleared by the Research Ethics Board at the University of Windsor.

### **Authors' Contributions**

All authors contributed to the design of the project. D.S. and K.P. were responsible for data collection, management and analysis. M.H. and D.S. wrote the manuscript. All authors (M.H., K.P., D.S., L.D., D.M., M.Z., and R.U.) participated in data interpretation and contributed to the critical revision of the paper and approved the final manuscript for publication.

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