

# Implementing and improving designated care partner programs in three Ontario long-term care homes

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## Abstract

Long-term care (LTC) residents have an increased risk of social isolation and loneliness, and these risks were exacerbated by pandemic policies that restricted visitors. The designated care partner (DCP) program was introduced in some LTC homes to allow designated family members to safely enter the homes and provide support for residents. We undertook a developmental evaluation (DE) to support the development and implementation of the DCP program in three Ontario LTC homes during the COVID-19 pandemic. Data were collected from 65 staff and DCPs through seven iterations of a DE process. Analysis used directed and inductive coding and theming procedures to create a description of the DCP experience. Themes illustrated the barriers and facilitators to the DCP program and revealed a pervasive deficit of care due to inadequate funding, staff shortages, and an acrimonious relationship between staff and family members. Our project demonstrated a need for additional resources and stronger partnerships between staff and family caregivers.

**Key words:** long-term care, developmental evaluation, family caregivers, COVID-19

## Introduction

The COVID-19 pandemic devastated long-term care (LTC) homes throughout the world, revealing longstanding deficiencies in this sector (Declercq et al. 2020; Estabrooks, et al. 2020; Hsu et al. 2020; Heckman et al. 2021). Canada has the unfortunate distinction of having the highest proportion of COVID-19 deaths (81%) occurring in LTC among all OECD (Organization for Economic Co-operation and Development) countries (OECD average: 38%) (Canadian Institute for Health Information 2020). One of the earliest reports (Hsu et al. 2020) estimated a case fatality rate of 36% (range 20%–42%) among residents in Canadian LTC homes and, based on publicly available information from official sources at that time, reported that deaths in LTC residents represented up to 85% of all Canadian COVID-19 deaths (Canadian Institutes for Health Information 2020; Hsu et al. 2020).

After the first wave of the pandemic, the Premier of the Canadian province of Ontario promised to defend residents with an “iron ring”. However, the second wave resulted in a greater number of deaths among LTC residents. By December 2020, 2479 LTC residents had died of COVID-19 in Ontario (63% of the provincial total) (Science Table COVID-19 Advisory for Ontario n.d.).

During the summer of 2020, Healthcare Excellence Canada (HEC), a nonprofit organization funded by the Canadian federal government, investigated the situation in LTC homes. In a report issued in July, they identified six “promising practices” that experts agreed were vital for assuring the ongoing stable operations of LTC homes and the safety of LTC residents during future waves of the pandemic (HEC 2020).

HEC then partnered with other funding organizations and announced support for 14 implementation science (IS) teams that partnered with LTC homes to implement one (or several) of these promising practices (HEC 2022).

LTC residents are at increased risk of social isolation and loneliness (Freedman and Nicolle 2020), which were exacerbated by pandemic policies that required social distancing, restricted visits from families and friends, and limited interactions with other residents (Hado and Feinbert 2020; Chu et al. 2021; Veiga-Seijo et al. 2021). With these facts in mind, our group focused on a promising “presence of family” practice calling for family members to be allowed into the LTC homes during the pandemic to care for their loved ones. We used a developmental evaluation (DE) approach to support the development and implementation of the “presence of family” practice in LTC homes during the pandemic. This pa-

per presents our DE methods and the results of an analysis of the data generated through this process.

## Methods

Our 12-month project included partnerships with three LTC homes, an advisory group of key stakeholders (most of whom were leaders of organizations that supported the provincial LTC sector, along with leaders and essential care partners from the participating homes), and several LTC residents and family members. To help guide our work, we undertook a rapid scoping review (Palubiski et al. 2022) to identify relevant literature concerning family caregivers entering into LTC homes during emergency conditions. Our review found that existing evidence was based primarily on expert opinion (Palubiski et al. 2022).

The three homes in our study were implementing a designated care partner (DCP) intervention to allow some family members to enter the home during the pandemic. This DCP program was an LTC adaptation of the Caregiver ID Program (developed by The Change Foundation and Ontario Caregiver Organization) and the Canadian Foundation for Healthcare Improvement's "better together" process (Canadian Foundation for Healthcare Improvement 2020; Ontario Caregiver Organization n.d.). The DCP program includes a process to identify essential care partners who provide personal, social, psychological, emotional, and physical support for residents. The program includes orientation and training, a commitment to follow safety protocols and use ID badges, and access to essential care partners to the home.

We were introduced to the leaders of the three homes by members of our advisory group. We shared our research objectives and methods with these leaders, answered questions, and then reached an agreement to work together. That agreement included the stipulation that participation in our project would be entirely voluntary for all employees working in the homes, as well as residents living in the homes and their essential care partners.

In November 2020, we learned that our proposal had been accepted and we received funds to conduct our work over a 12-month period.

Our group followed a DE approach (Fagen et al. 2011; Patton 2011), drawing on our group's prior experience with this method (Conklin et al. 2015; Elliott and Stolee 2015). DE is based on the notion that human systems (such as LTC homes) are complex adaptive systems and is focused on the way in which people intend to use the results of the evaluation (Patton 2011, 2017). This evaluation method is suited to situations that are ill-defined and characterized by high levels of uncertainty, such as the effort to enhance health and well-being in a LTC home during a global pandemic. DE also creates a social learning environment that informs effective action to bring about positive change, and is thus aligned with organizational change theories that posit that change agents must often produce learning that brings about improvement and transformation (Argyris and Schön 1978; Patton 2011; Conklin 2021). We selected DE as the project's implementation approach because it was well suited to the complex situation faced by the three homes we had part-

nered with and because the leaders of these homes were both sympathetic to and had experience with the use of social learning processes to facilitate positive change (the homes were participating in a learning collaborative coordinated by one of the organizations in our advisory group).

We used DE to enable a continuous improvement process as the homes implemented their DCP interventions. DE recognizes that given the complexity of human systems, interventions need to be tailored to the unique features of specific social environments (Hummelbrunner 2011; Patton 2011; Kania et al. 2012). In essence, a DE approach sees evaluators collect data about the intervention's operation within a complex milieu and then use the data to help the program team make improvements (McLaughlin 1976; Patton 2011).

We created DE core teams (DECTs) in each of the three participating LTC homes to provide oversight and assistance to our DE process. The DECTs were composed of representatives of the LTC homes' management as well as DCPs and residents who were involved in the DCP program. One person on each DECT was designated as our "primary contact" in the home (in all three homes, the person taking this role was a staff member at a program management level). DECT membership includes the following:

- Home 1: Two DCPs, one resident, one corporate vice president, and a program director (five members).
- Home 2: Two DCPs and one administrative staff from the participating home (three members).
- Home 3: One DCP, one resident, one manager from the participating home, and one corporate representative (four members).

We originally intended to bring the three DECTs together in combined planning meetings and feedback sessions so they could hear about what was happening in the other homes. However, the exigencies of the pandemic made this impossible. When we began the DE work, one home was dealing with a COVID-19 outbreak, another was finalizing organizational changes, and only one home was ready to begin. The DE process was therefore governed by different timelines in each home, and it was not possible to jointly plan and debrief each DE iteration with all three homes at the same time. However, we did allow for sharing across the homes through the regular meetings of our advisory group (which included representatives from each home).

The DE process involved initial planning meetings, an inquiry process that implemented the plans, and feedback sessions where findings were shared and new plans were created. We had intended to carry out five iterations of this process with each home. Again, the realities of the pandemic intervened, and we ended up completing two iterations with two homes and three with one home.

During initial planning meetings, the DECTs identified questions and concerns they wanted the research team to investigate. In subsequent DECT feedback sessions, findings were presented, and the DECTs considered improvements to their implementation process and established new questions for the researchers to investigate in the next DE iteration.

All DECT meetings were held on the Zoom videoconferencing platform.

The research team initially intended to recruit five DCPs and five staff members at each LTC home (thirty participants across the three homes). The DECTs and research team agreed that this would provide an appropriate range of diverse experiences to reveal facilitators and barriers to the implementation of the DCP program. In this case, however, our results exceeded our expectations, and we recruited 65 participants (34 staff and 31 DCPs). Participating staff were directly involved with the DCP program, representing various roles within the home: registered nurses, registered practical nurses, personal support workers (PSWs; other jurisdictions term this role Health Care Aide or Resident Care Aide), therapeutic recreation staff, managers, dietitians, pastoral care workers, and Behavioural Supports Ontario staff (a provincial team specializing in dementia care).

Before our DE began, each home's primary contact announced the project to potential participants (including residents, family members, and staff who were participating in the DCP program). Interested people were invited to contact the research team. After obtaining informed consent, the research team conducted interviews (using protocols developed in collaboration with the DECTs) in the individual's language of choice—English or French.

Interviews, approximately 30 min long, were conducted by Zoom or telephone. If participants consented, interviews were audio-recorded, and the interviewer created detailed notes while listening to the recording after the interview was complete. If the participant did not consent to a recording, the interviewer made detailed notes on a computer during the interview. Interview notes were later anonymized.

During subsequent iterations, the research team approached people who had signed consent forms. Some participants were interviewed once, while others were interviewed up to three times.

We used two analytical procedures. The first allowed us to work quickly and produce results that the DECTs used to consider real-time improvements to their implementation process and also to generate new questions about the functioning of the program. The second procedure was used when all iterations were complete and all DECT feedback sessions had been held. This procedure was intended to take another look at the data to ensure our rapid process had revealed all relevant meanings latent in the data set.

Our first analytical procedure involved a deductive (directed) coding approach, and the second used an inductive (open-ended) coding and theming approach (Hsieh and Shannon 2005; Braun and Clarke 2006; Patton 2015). Together, these procedures allowed us to find answers to the questions posed by the DECTs and also to consider whether the data set could support additional insights about the DCP programs in the participating homes. This paper reports the overall findings from both analytical procedures.

A comprehensive written record of each interview was created based on the interview notes and recordings. The data were imported separately for each LTC home into NVivo software for analysis. One analyst (MM) used the interview ques-

tions as nodes and proceeded to code participant data (see Supplementary Material 1 for the interview protocols).

After coding was complete, the analyst prepared a detailed findings report. The reports were organized with interview questions as headings, followed by a description of interview responses to the question. This report was reviewed by a second (JC) and sometimes a third (JE) analyst, who identified areas needing further consideration. The report was then finalized. Two researchers (JC and MM) met with the home's DECT to share findings, facilitate a discussion of possible improvements to the DCP implementation process, and identify new questions that could be the basis for the subsequent DE iteration.

For the second analytical procedure, one member of the research team (JE) reviewed the interview audio recordings and considered whether the seven findings reports (one for each iteration at the three homes) were a clear and complete presentation of the meaning of the data. This exercise served to confirm the findings and conclusions in the reports. The exercise also allowed the team to extract some illustrative quotations for the main findings. Then, using an inductive approach, the research team coded all reports to identify themes characteristic of the three homes.

Details on our qualitative methods can be found in Supplementary Material 2.

The research protocols were reviewed and approved by the Research Ethics Board of the Bruyère Research Institute (REB protocol M16-20-068) and the University Human Research Ethics Committee of Concordia University (certificate 30014706).

## Results

Given the contextual nature of our findings, we begin with a description of the participating homes. This is followed by a description of the themes that were common among all three participating homes and the themes shared by two homes. We then describe the themes unique to individual homes.

The characteristics of the participating LTC homes during the time when we conducted our interviews are presented in Table 1. The characteristics of the DE participants who contributed data during our data-collection processes in each of the three DE iterations are summarized in Table 2.

Our analysis yielded 21 themes characteristic of the homes that participated in our study. Table 3 shows all themes that were identified through the analysis.

Our analysis identified six themes that were common to all three homes and five themes that were common to two of the three homes. We describe these 11 themes in the following sections, along with the 10 themes that were unique to one home (the themes unique to a single home are more fully described in Supplementary Material 3).

### Themes shared by all three homes

Table 2 indicates that our analysis yielded six themes characteristic of the situation in all participating homes. We describe these themes below.

**Table 1.** Profile of the three participating homes.

	Home 1	Home 2	Home 3
Facility type	For profit	Not-for-profit	Municipal
Location	Small community	Urban setting	Small community
Number of beds	100	198	66
Language spoken in home	English	French and English	English
Number of residents	78	198	66
Number of PSWs	80	147	54
Number of physicians	2	7	1
Number of nurse practitioners	0	1	0
Number of RNs	7	21	7
Number of RPNs	12	39	13
Number of recreation staff	4	5	8

**Table 2.** Participants in the data-collection process.

<i>Iteration 1 of the DE process</i>	
Home 1	<ul style="list-style-type: none"> <li>Five family members who act as DCPs</li> <li>Five staff: registered nurse, registered practical nurse, program director, executive director, and recreational staff member</li> </ul>
Home 2	<ul style="list-style-type: none"> <li>Four family members and one volunteer who act as DCPs</li> <li>Five staff: two PSWs, two nurses, and one on-site practitioner employed by Behavioural Supports Ontario (experts in dementia care)</li> </ul>
Home 3	<ul style="list-style-type: none"> <li>Five family members who act as DCPs</li> <li>Five staff: two PSWs, one nurse, one recreational staff member, and one on-site practitioner employed by Behavioural Supports Ontario</li> </ul>
<i>Iteration 2 of the DE process</i>	
Home 1	<ul style="list-style-type: none"> <li>Three family members who act as DCPs</li> <li>Five staff: two recreational therapists, one pastoral care worker, one PSW, and an executive director</li> </ul>
Home 2	<ul style="list-style-type: none"> <li>Three family members who act as DCPs</li> <li>Five staff: two PSWs, one nurse, one dietician, and one recreational staff member</li> </ul>
Home 3	<ul style="list-style-type: none"> <li>Five family members who act as DCPs</li> <li>Five staff: two PSWs, one nurse, one recreational staff, and one on-site practitioner employed by Behavioural Supports Ontario</li> </ul>
<i>Iteration 3 of the DE process</i>	
Home 3	<ul style="list-style-type: none"> <li>Five family members who act as DCPs</li> <li>Four staff: two PSWs, one recreational staff, and one on-site practitioner employed by Behavioural Supports Ontario</li> </ul>

## Presence of family has a positive impact on residents' mental and physical health

Staff and DCPs observed notable improvements in residents' mental and physical well-being after the implementation of the DCP program. One DCP (Home 3) commented, "This [program] has been a life saver during COVID. For residents to have family in their room visiting, this has been really really important". Another DCP (Home 3) said, "I would have lost my mom without being able to be with her if this program hadn't been in place for as long ... you know, the last year and a half, none of us would have been with her. That would have been very difficult". Staff also noticed positive changes when DCPs were allowed to visit residents, as indicated by this PSW (Home 2) comment: "when the DCP program started, you saw just a shift in mood and environment with, you know, residents being much happier and, you know, having one-to-one contact with their loved ones or families and as an employee myself, I find that the experience has been a lot more pleasant".

Families offered emotional support to residents and interacted with them in ways that were unavailable during the severest lockdowns. Staff participants pointed out that re-

sponsive behaviours rose during the initial lockdown period when families were barred from LTC homes (responsive behaviours refer to the way a person living with dementia may behave when experiencing confusion or frustration). Residents with dementia became more confused, did not understand why they were being isolated, and were troubled when they saw staff wearing unusual personal protective equipment (PPE). During that period, many families were reluctant to visit residents by standing at a window or by using a virtual platform because a variety of unpredictable factors—such as the sun's glare on a window or poor audio transmission on computers—could confuse residents and cause more frustration.

When families re-entered the homes, responsive behaviours rapidly declined. Some staff were astonished that although a resident with dementia might sometimes be unable to recognize their family members, these family members were nonetheless uniquely able to reduce their loved ones' agitation.

In addition to improvements in mental health and well-being, families contributed to residents' physical health by monitoring food portions, taking residents to external



**Table 3.** Summary of themes from the analysis.

Theme	Home 1	Home 2	Home 3
<i>Themes common to three homes</i>			
Presence of family has a positive impact on residents' mental and physical health	✓	✓	✓
The primary role of DCPs is to provide vital emotional and social support	✓	✓	✓
The number of DCPs per resident should be increased	✓	✓	✓
There was inconsistent DCP compliance with Infection Prevention and Control (IPAC) protocols	✓	✓	✓
DCPs need to participate in care conferences	✓	✓	✓
Family councils are an untapped resource	✓	✓	✓
<i>Themes common to two homes</i>			
Some challenges arose with the DCP-staff relationship		✓	✓
PSW staffing shortages and poor work conditions created challenges		✓	✓
Some families are not participating in the DCP program	✓		✓
Communication is generally effective but could be improved	✓		✓
Does the DCP program have a future?	✓		✓
<i>Themes unique to one home</i>			
Importance and success of the screening and training process	✓		
The usefulness of informing staff about upcoming DCP visits	✓		
Some rules produced unintended negative consequences	✓		
The centrality of residents during DCP visits	✓		
Challenges arose from language barriers and inadequate personal services		✓	
There were misunderstandings and negative communication/interactions between DCPs and staff		✓	
Some things changed when pandemic restrictions began to be lifted		✓	
There were communication challenges, and important information was unavailable			✓
A variety of positive and negative reactions to the training of DCPs			✓
Limitations and challenges related to the physical attributes of the LTC home			✓

appointments, and informing LTC teams about physical changes such as wounds, bruises, and infections.

### The primary role of DCPs is to provide vital emotional and social support

All staff and DCP participants agreed that the DCPs' primary role is to provide psychosocial support to residents. To fulfil this role, family should be encouraged to visit as often as possible. Some suggested that DCPs also contribute to residents' well-being by helping with care tasks such as oral hygiene, hand care, and feeding. Some added that DCPs could assist staff with bathing and changing clothing, especially with residents who want to receive this help only from specific family members.

Some staff suggested that DCPs willing to provide hands-on care could receive special training. Most DCPs believed the training and orientations they received through the DCP program were sufficient. However, some DCPs of residents living with dementia were interested in attending workshops on how to support residents in moments of agitation.

### The number of DCPs per resident should be increased

Participants indicated that a rule stating that one resident could have only two DCPs was unduly limiting. One DCP (Home 3) commented, "I think the only thing would be if we were allowed more designated partners or more than one in

a room at time...just sharing the load a little better if there were more of us".

This limitation was seen as a challenge because some residents had large families, and additional children wanted to visit and offer care. Also, some DCPs found that the burden of providing care was onerous, and they would have appreciated having additional DCPs to share the workload.

### There was inconsistent DCP compliance with infection prevention and control (IPAC) protocols

Staff noted that some DCPs came to ignore IPAC rules. Reasons given for this included the belief that the situation was safer as more people were vaccinated, feelings of discomfort about wearing PPE, and the desire to remove physical barriers between the resident and DCP. Some staff frequently reminded DCPs to follow the rules, and this sometimes led to unpleasant interactions. As a result, staff suggested that DCPs should receive reminders or follow-up training about following IPAC rules.

### DCPs need to participate in care conferences

Both staff and DCPs acknowledged the importance of DCP participation in resident care conferences. Staff said that they benefited from DCP knowledge about residents' routines and preferences, and DCPs indicated that staff knowledge helped them (DCPs) to better understand their residents' physical and mental health. Some DCPs also indicated that

they would like to see and participate in more frequent care conferences.

## Family councils are an untapped resource

Although Ontario requires that LTC homes form and support a Family Council, staff and DCPs often seemed unaware of the functions and, at times, even the existence of family councils in their homes. This point arose because at times it seemed that a family council could address a need identified by participants, but when this point was raised by the interviewer, the participant indicated that they were unaware of their home's family council.

## Themes shared by two homes

**Table 2** highlights five themes characteristic of the two participating homes. We describe these themes below.

### Some challenges arose with the DCP-staff relationship

In Homes 2 and 3, some staff complained that DCPs would interrupt them while they worked, asking for immediate service. These staff said that most of these requested services were already scheduled to be completed at a later time. One staff member (Home 3) suggested these unwarranted interruptions could be mitigated by a punitive system that included warnings and penalties for DCPs who interrupted staff with unreasonable requests or who broke IPAC rules.

### PSW staffing shortages and poor work conditions created challenges

In Homes 2 and 3, some DCPs complained that PSWs were unavailable when needed. Some DCPs noted that PSWs had little time to assist them and were overworked. DCPs believed that this meant that staff could not check up on or socialize with residents as frequently as needed. These DCPs acknowledged that PSWs were doing their best and that the challenge was due to staffing shortages and low salaries.

Some DCPs were concerned that DCP contributions could be exploited by the government as an excuse to make no improvements to PSW staffing levels or salaries. In other words, family members could be seen as compensating for PSW shortfalls, and thus things could be left unchanged.

Staff also described their unsatisfactory work conditions. Some noted an unfair wage gap between PSWs working in hospitals and LTC homes. They pointed out that work in LTC homes is heavier than comparable work in hospitals. Some said that if they were not paid a fair salary, they would seek employment elsewhere. Some pointed out that raising PSW wages would produce greater stability and improved care that would also enhance the well-being of residents.

## Some families are not participating in the DCP program

Staff and DCPs in Homes 1 and 3 said that more families need to become DCPs because some residents had no one visiting or advocating for them. In some cases, a family member would sign up for the DCP program, complete the training and orientation, but rarely, if ever, visit the resident during lockdowns. In other cases, a resident would simply not have anyone volunteer as their DCP. Active DCPs would occasionally express concerns about the well-being of residents in this predicament. As one DCP (Home 1) said, "...people have to be advocates for their parents or whoever's in there that they're looking after. I just feel bad sometimes for the people that don't have people that, you know, can advocate for them or come and visit them".

## Communication is generally effective but could be improved

In Homes 1 and 3, staff and DCPs were satisfied with communications related to rules, policies, and updates on resident health. One DCP (Home 1) reported, "They have been fantastic at communicating all along". Another (Home 3) said, "It was very easy to get approved [as a DCP], and once I was approved, and once the information was being sent directly to me, I think that they've been very proactive about keeping me informed". DCPs were also satisfied with the availability of managers, with one DCP (Home 1) saying, "[Name of manager] is very good at communicating with the designated care partners". Staff and DCPs reported receiving phone calls, emails, newsletters, and mail, and having easy access to managers and websites for additional information.

However, specific areas could be improved. For example, some DCPs said that emails were inconsistent, lengthy, and complicated. Some staff said they occasionally needed to meet one-on-one with DCPs to explain emails. Staff also acknowledged that pandemic rules frequently changed and that it was challenging to keep track of updates and revisions. The same DCP quoted above commented, "It's difficult when it seems like the rules change all the time".

## Does the DCP program have a future?

Most staff and DCPs said that the DCP program should continue after the pandemic and be improved with more frequent and precise communications. As one DCP (Home 3) said, "Yes, I think that [the DCP program] should be continued. Because even during an outbreak, people need to see other people". Many staff members agreed. One staff member (Home 3) commented, "I think it's an absolutely excellent idea. I know there are certain families you get to see on a regular basis because they're very involved with mom or dad or aunt or uncle or grandma. And they come on a regular basis. I think if moving forward, we could get that for every resident".

However, a few staff and DCPs saw no need for continuing the program; some DCPs saw the program as giving them a formal title and role that covered precisely their pre-pandemic role, and they believed that continuing the program after the pandemic would serve no purpose. Similarly, some staff were concerned that continuing the program might inhibit visits from nonregistered family and friends and thus decrease quality of life. Some staff felt that the program should be paused temporarily so that people could enter the LTC homes without restrictions and then be resumed if another outbreak happens.

## Themes unique to individual homes

**Table 3** identifies the eight themes that are unique to just one of the three homes participating in our project. Supplementary Material 3 offers a description of each of these themes. Here we provide a brief paragraph description of the themes that are unique to each home.

### Themes unique to Home 1

Home 1 is a small for-profit home located in a small town in southern Ontario that is relatively close to several populous centres (for example, the home is about 100 km from Hamilton, 65 km from London, and 44 km from Kitchener-Waterloo). The themes unique to this home had both positive and negative elements and concerned training and communications issues, along with some surprising consequences produced by the DCP program.

Our evaluation indicated that research participants in this home had a positive experience of the DCP program implementation and attributed this success in part to a smooth and simple screening and training process. When asked how the program could be improved, staff suggested that the training of DCPs could be strengthened to facilitate more meaningful visits and to help DCPs learn how to interact effectively with residents living with dementia. Both staff and DCPs in Home 1 also felt that the program's success was due in part to the home's practice of allowing DCPs to inform staff about upcoming visits. This information allowed staff to accommodate the DCPs by adjusting the residents' schedules.

However, Home 1 participants also reported some surprising and sometimes negative results. For example, residents and families were frustrated by pandemic rules that prevented residents from going outside, and some DCPs reported that these rules contributed to a deterioration in their residents' health or well-being. Another more positive result of the DCP program was that during the pandemic, DCP visits tended to put the resident in a more central position. Before the pandemic, families tended to visit in groups, and they would visit with and talk to each other, with the resident often seeming somewhat marginalized during the visit. During the pandemic, DCP visits seemed more "intentional", with attention focused entirely on the resident.

### Themes unique to Home 2

Home 2 is a large, bilingual LTC home located in an urban centre whose catchment area includes a population of

approximately 1.5 million. The themes unique to this home had more negative than positive elements and concerned language barriers, inadequate services, and misunderstandings, as well as improvements that were noticed when pandemic restrictions finally eased.

This home was characterized by more challenges and difficulties than the two smaller homes in our project. For example, DCPs identified language barriers that arose when anglophone residents were unable to communicate their needs to staff with limited English language skills. Some DCP participants also noted that their residents received little personal grooming during lockdowns and reported a lack of respect for their privacy. One DCP in Home 2 said they were not invited to a single care conference over a period of three years, despite multiple requests, and another DCP said that their resident's requests for an electric wheelchair were turned down when a nurse said that the wheelchair was too expensive given the amount of time that this resident was going to be alive. DCPs from this home also complained about food being served that was inconsistent with residents' dietary restrictions.

Staff in Home 2 also noted challenges, including residents displaying responsive behaviours that seemingly arose due to their isolation during the pandemic. Staff also said that some DCPs behaved unpleasantly and described incidents involving yelling, complaining, and blaming. They said that some DCPs made their jobs harder by expecting them to be always available. There were also occasions when staff would ask DCPs to provide needed personal items, such as suitable clothing, and DCPs would ignore these requests. Staff also told us that some DCPs would alter a resident's routine without consulting health care staff, resulting in misunderstandings and conflict.

DCPs had their own perspectives on relations with staff. According to some DCPs, staff would be available for a medical emergency, but for more routine matters, they were often unavailable. Consequently, some DCPs stopped asking questions.

DCPs in Home 2 said that when pandemic restrictions eased, they felt more confident about moving around the home and seeking assistance. Nurses in the home also noticed a decline in the frequency of demands when DCPs were permitted to leave resident rooms and access materials or information on their own. During periods of more severe restrictions, DCP requests were sometimes perceived as *orders* rather than requests. Recreation staff also reported improvements when restrictions eased and said they were able to reinstate various recreational and therapeutic activities. PSWs, however, did not report noticing any changes in the frequency or types of requests from DCPs as restrictions eased.

Staff in Home 2 said that the participation of two DCPs on the DCP program steering committee shed light on DCP frustrations. For example, the DCPs explained why it was frustrating for them to be confined to the resident room without the ability to communicate with staff. Staff commented that they were working in their "bubbles", and having DCPs available to offer a different perspective was helpful.



### Themes unique to Home 3

Home 3 is located north and west of the more populous urban centres in the province and is more than a 2 h drive from the nearest large urban area. The themes unique to this home had both positive and negative elements and concerned issues related to training and communication, as well as the physical layout of the home.

Participants in this home experienced some communication challenges as the DCP program was introduced, with DCPs unsure of their responsibilities in the initial stages of implementation. Some staff (mainly PSWs and kitchen and cleaning staff) were not involved in the early DCP program planning, and this led to some hesitation toward the program. Staff were worried that family visits could increase the danger of introducing the virus into the home. This cautious attitude toward the program changed when staff witnessed firsthand the positive effects of DCPs' presence on residents (particularly those with responsive behaviours) and when vaccinations and rapid in-house testing were introduced.

DCP participants in Home 3 experienced the DCP training in diverse ways. Some appreciated the training and asked for more, while others found it overwhelming.

DCPs at Home 3 also mentioned challenges related to specific attributes of that home. For example, DCPs complained about the availability of only one bathroom for them to use. Also, DCPs were not permitted to eat in the resident's room and did not have any DCP-allocated rooms that they could use. These issues reduced the duration of visits for more elderly DCPs and those who travelled long distances to visit Home 3.

### Discussion and conclusions

This research responds to recent calls for interdisciplinary and collaborative approaches in response to the COVID-19 pandemic (Meisner et al. 2020). Wister and Speechley (2020) issued a specific challenge for research that examined the positive adaptations of people and communities to the pandemic. Our DE approach provided an opportunity for positive adaptations in three LTC homes.

Our most significant finding is the recognition by virtually all participants of the importance of the care provided by DCPs. This care is *essential*. The DCP program was viewed by almost all participants as a success. Our participating homes are now considering how the DCP program might be institutionalized and how to better support the care provided by family and friends. Our findings are consistent with recent studies confirming the importance of care provided by family (Kemp 2021) and also confirm studies showing that LTC homes that responded proactively and creatively to the pandemic have fostered a variety of positive outcomes for residents and families (Palacios-Ceña et al. 2021; Gallant et al. 2022). The findings reported here also support studies suggesting that attitudes toward the care provided by families may be changing and that the conditions may now be in place to transition the culture of LTC homes toward patient-centred care that emphasizes selfhood, human relationships, and

strengthened partnerships between staff, family, and those who receive care (Kemp 2021; Mackenzie 2022).

Our findings also confirm that DCPs recognize that the care provided by frontline workers, especially PSWs, is essential and are aware of challenges (related to workload, working conditions, and pay scales) that make the work of PSWs difficult. Many DCPs stated that they recognize that the LTC sector needs additional resourcing to improve basic care and PSW work conditions. These findings are consistent with studies showing that when families were barred from LTC homes, the workload of staff increased, sometimes leading to exhaustion and burnout (Hugelius et al. 2021; Low et al. 2021; Palacios-Ceña et al. 2021; Smaling et al. 2022).

The growing recognition of the importance of care provided by DCPs and the likelihood that health leaders may be exploring ways to support that care could have the unintended consequence of reducing pressure on the government and managers to increase basic care resources in LTC homes. This report is not intended to disparage the importance of basic care provided by PSWs and other staff, but rather to highlight the need for a new partnership and for better LTC resourcing.

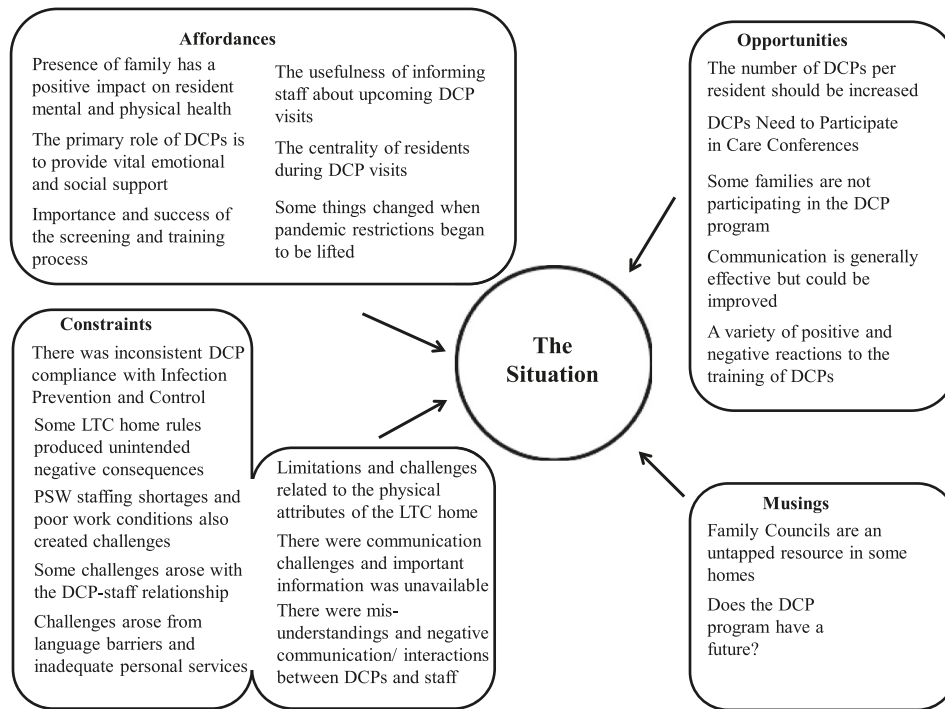
Our work has also brought to light some pragmatic findings about implementing a visitation program such as the DCP program. In our participating homes, DCP training, communication, and informal interactions were considered to be "good enough" during the pandemic, although participants suggested areas for improvement. The one-size-fits-all approach to training could be improved by tailoring training to the needs of specific residents and DCPs. Moreover, training updates should be offered when circumstances change. Those responsible for communications should analyze DCP communication requirements and should highlight the most important information for easy access. DCPs also often need to interact with staff during visits, and finding ways to normalize and support these interactions is important.

Our findings suggest that every LTC resident needs a DCP, and when possible, a resident should have multiple DCPs who provide care ranging from the psycho-social support that occurs when people spend time together to some elements of basic care such as feeding, bathing, and grooming residents. DCPs also monitor the health of residents; by spending time with a resident, they often notice new situations that they bring to the attention of staff. DCP participants also told us that there were times when staff were reluctant to listen or take action. DCPs stated that they must advocate on behalf of the resident, ensuring that LTC health care staff take note of situations requiring action. This is consistent with the findings from Dupuis-Blanchard and colleagues (2021), which reveal the importance of family members' advocacy roles.

Although our findings indicate the overall success of these DCP programs, they also reveal a general and pervasive deficit in care. Table 2 shows the thematic summary that resulted from our analysis. These themes represent the patterns of thought, behaviour, and structuring characteristic of the situation in our participating homes. The themes, in other words, correlate with the prevailing situation and can be called upon to describe specific aspects of that situation. They are part of a



**Fig. 1.** Affordances, constraints, opportunities, and musings.



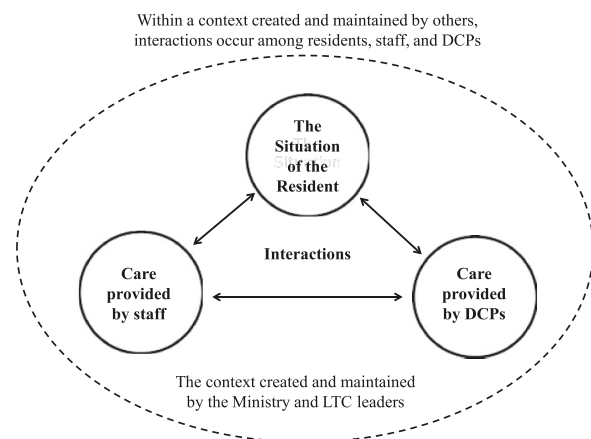
web of behaviour, or more specifically, a web of sensemaking behaviour, which is the reality of these social milieus.

Clustering these themes can reveal additional meanings. For example, Fig. 1 suggests that some themes reveal the affordances of the situation they describe—the congenial aspects and positive outcomes characteristic of the homes. Other themes reveal constraints, limitations, and challenges. Other themes reveal opportunities to improve, and still others represent musings within these human systems about their future.

The situation depicted by these factors sees ongoing interactions among residents, staff, and DCPs, and these interactions often have to do with providing and receiving care as well as an ongoing effort to respect the dignity of the resident, the frontline staff, and the DCP as they seek to support their residents (see Fig. 2). We might also say that the themes reveal a relational context—a web of relationships among residents, staff, and DCPs within a context that is created and maintained by health officials who set and enforce the standards of care and by LTC leaders who manage budgets and work routines.

Ultimately, the themes reveal a social world in which a natural partnership between those providing care is not able to take hold, where a deficit of care is experienced by too many, and where these shortfalls are institutionalized in a system that is founded on a mindset of accountability and compliance rather than one of learning and relational care. Paid and unpaid care providers struggle to meet the needs of residents who seek care and to form strong and supportive partnerships to meet those needs. Some residents languish in isolation and neglect, and the LTC milieu fails to provide an adequate “holding environment” to support those who are providing and receiving care (Kahn 2001, 2005, 2019; Conklin

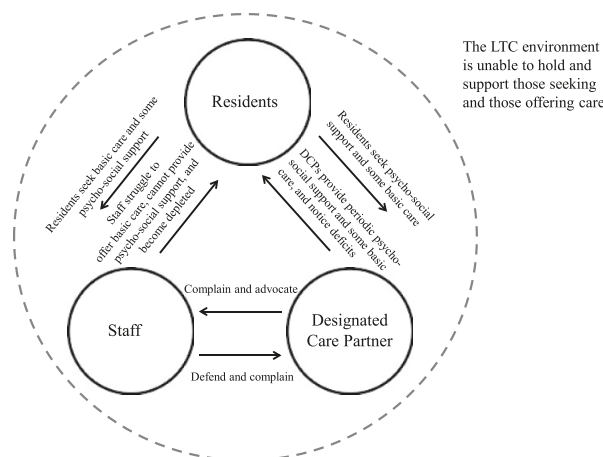
**Fig. 2.** Careseeking and caregiving interactions within the LTC context.



2009; Barton and Kahn 2019). Figure 3 reveals this ongoing, unwholesome dynamic.

Residents need care, and these needs are satisfied first by the care providers employed by the LTC home. However, during the COVID-19 pandemic, this care often failed to meet residents’ needs, and the shortfall was attended to (for some residents) by the efforts of DCPs who met some psycho-social needs and helped with the resident’s basic care. This compensatory care provided by DCPs was offered without the benefit of a full partnership with caregiving staff, and gaps frequently appeared in the form of unmet needs. These gaps arose in part because the resident’s health and well-being are not static but continue to change as the

**Fig. 3.** The structuring of a deficit of care.



resident ages and adapts to the LTC milieu, creating the need for DCPs to become advocates who call attention to the care deficits that undermine a resident's health and well-being.

Moreover, the experience of providing care during the pandemic caused staff and DCP caregivers to become depleted. They thus encountered the need to be restored and made whole again. Because these caregivers at times act more as adversaries than partners, they do not adequately support each other. In addition, the LTC home is not able to adequately support the caregivers, given the need to focus on Ontario's fulsome LTC compliance regime and on an array of new and changing pandemic requirements and to deliver care within a tightly controlled and inflexible budget. Acrimony and disputes arose between paid and unpaid caregivers, and LTC leaders sought to manage these conflicts and maintain stability within the hard-pressed workplace. The result was an unhealthy and depleting dynamic within some LTC homes where groups with the potential to become partners instead functioned as adversaries and where leaders were able to do little more than resolve disputes and do their best to comply with standards imposed by external authorities.

We offer this model as a contribution to the growing conversation about how to improve the LTC sector in Canada and other developed countries. The resident needs care; this care must be improved, and one of the most immediate ways of promoting this goal is to create the conditions for a new partnership between LTC frontline staff and DCPs. In addition, LTC leaders must recognize the needs of frontline staff, and these needs must be better understood and attended to. DCPs often also have challenges and needs, and these must be considered as well.

Our final suggestion is that efforts to improve the LTC sector must be carried out with the meaningful participation of all key stakeholders, including family members and frontline staff, in all aspects of program design and implementation. For decades, the social science of organizational change has shown that meaningful stakeholder participation is a factor critical to the success of change initiatives. As early as 1960, [White and Lippitt](#) asserted that "Of all the generalizations growing out of the experimental study of groups, one of the

most broadly and firmly established is that the members of a group tend to be more satisfied if they have at least some feeling of participation in its decisions" (1960, p. 260). Recent studies confirm that the principle of stakeholder participation is often associated with successful efforts to introduce improvements in organizational milieus ([Stouten et al. 2018](#)). Our findings include observations from participants indicating that the ability to participate in the design and operation of the DCP program contributed to more positive feelings toward the program. This provides support for the suggestions of [Cosco et al. \(2021\)](#) and [Meisner et al. \(2020\)](#) about the role of co-design approaches in addressing the social isolation and other challenges experienced by older adults as a result of the pandemic.

Co-design and collaboration were also characteristics of how we carried out our DE process and produced the results that are reported here. Our experience confirms that DE is well suited to inquiries into highly uncertain and complex social phenomena ([Patton 2011](#); [Conklin 2021](#)). As policymakers consider how to design and implement improvements in LTC homes and processes as a result of our pandemic experience, we suggest that serious attention be paid to the utility of social learning processes such as DE.

A new and supportive partnership between staff and families is one of the needed improvements in the LTC sector, and the process to design and implement this improvement must itself be based on a spirit of partnership and collaboration.

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### Data availability

The primary research data are housed securely at the Bruyere Research Institute in Ottawa, Canada. The dataset can be obtained from the corresponding author on reasonable request.

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### Competing interests

The authors declare that they have no financial or non-financial competing interests concerning this article.

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## Supplementary material

Supplementary data are available with the article at <https://doi.org/10.1139/facets-2022-0253>.

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