INTRODUCTION

With growing evidence supporting person- and family-centred care (PFCC), there is increasing demand for healthcare providers to partner directly with patients and caregivers in care planning and delivery (Backman et al., 2018; Giosa et al., 2019; Kogan et al., 2016). While there is no single unifying definition of PFCC, individual choice and personal autonomy are key distinguishing factors from traditional biomedical models of care delivery (Cott, 2004; DiLollo & Favreau, 2010; Edvardsson & Innes, 2010; Edvardsson et al., 2008; Institute for Patient- & Family-Centred Care, n.d.; Kogan et al., 2016). Goal-setting has been cited as a key opportunity to...
operationalise PFCC in care planning, particularly in settings where care is delivered in individuals’ personal environments (Furze, 2015; Giosa et al., 2019; Gray et al., 2020; Oksavik et al., 2021; Sanerma et al., 2020). Person- and family-centred goal-setting requires an understanding of patient and caregiver values to ensure care aligns with their priorities and preferences, as well as to improve communication between patients and their healthcare providers (Carroll, 2011; Duchan & Black, 2001; Kogan et al., 2016). Active patient involvement at the beginning of the care planning process has been demonstrated to be critical to facilitating decision-making in community-based care (Manhas et al., 2021) and the delivery of integrated care more broadly (Czypionka et al., 2020).

Pervasive societal ageism and paternalistic decision-making in healthcare delivery can lead to inaccurate assumptions that older adults prefer less active roles in care and decision-making (Levinson et al., 2005; Schulman-Green et al., 2006; World Health Organization, 2021), or that all older adults’ goals are the same and/or that they do not have goals (Schulman-Green et al., 2006; Sockolow et al., 2017). Evidence suggests that community-dwelling older adults highly value their autonomy (McDonald et al., 2021) and have a diverse range of goals pertaining to their health, living accommodations, relationships and mobility (Robben et al., 2011). Collaborative goal-setting with older adults is an important motivator for participation in self-management of illnesses and disease (Vermunt et al., 2017), with benefits to physical and mental well-being (Cheng, 2018).

In home care, systemic barriers such as limited time, task-based delivery models and providers working in isolation of one another can inhibit goal-setting opportunities and practices at the point-of-care (Manhas et al., 2021; Sockolow et al., 2017). Goal information is often not recorded in these settings, and if goals are identified, they typically pertain to individual elements of clinical care and are not written in the client voice or integrated across providers (Giosa et al., 2021; Robben et al., 2011; Sockolow et al., 2017). Person- and family-centred goal-setting has the potential to integrate the contributions of the various providers involved in geriatric home care so that they are all working towards a common goal (Gray et al., 2020; Parsons et al., 2012; Redding, 2013). Understanding how goal-setting in home care could be more person- and family-centred for older adults could improve experiences of integrated care within the sector.

In this study, we aimed to determine how client goal-setting practices in home care could be re-oriented around older adults’ self-perceived goals, needs and preferences.

2 | METHODS

2.1 | Study design

A qualitative research design (Patton, 2002) was adopted to pursue an in-depth understanding from older adults and caregivers on how to better incorporate their voices in goal-setting at the point-of-care in home care. Previous research has revealed poor experiences of older adults and their caregivers with care planning across the healthcare system, including home care (Stolee et al., 2019). Instead of replicating previous findings, we took a solution-focused approach to encourage older adults and their caregivers to share ideas for changing how they are engaged in goal-setting in the planning phase of their care, based on their own lived experiences (Proudlock & Wellman, 2011; Walsh et al., 2006). The solution-focused approach is rooted in counselling and therapy practices and is future-focused, goal-directed and aimed at searching for solutions rather than focusing on problems (Proudlock & Wellman, 2011; Walsh et al., 2006). There are three discourses that are important in a solution-focused approach:

1. The Change Discourse: involves identifying strengths and qualities that will facilitate positive change as well as goals for the change instead of focusing on the problems;
2. The Solution Discourse: involves identifying what the world would look like if the problem was solved; and
3. The Strategy Discourse: involves developing an action plan with tasks to be performed (Bloor & Pearson, 2004).

2.2 | Data collection

2.2.1 | Setting

This study took place in Ontario, Canada where, at the time of this study there were 14 Local Health Integration Networks (LHINs) responsible for allocating funds and coordinating home and community care (Local Health Integration Networks, 2014). The LHINs contracted direct service provider agencies to provide point-of-care services (Health Council of Canada, 2012; Home Care Ontario, 2014).
2.2.2 | Participants

Inclusion criteria for key informant interviews included that participants were older adults aged 65 years or older who were current or previous (within 5 years) recipients of publicly funded home care services in one LHIN. Self-identified caregivers of these older adult home care recipients were also eligible to participate. There were no exclusion criteria for participants who met the inclusion criteria. Convenience sampling through community advertisement served as the main recruitment strategy, with an aim to recruit up to 25 participants according to qualitative sampling guidelines to reach saturation (Bernard, 2000; Green & Thorogood, 2009). Convenience sampling strategies in qualitative health research have been criticized for introducing self-selection bias into study findings due to the non-random nature of participant selection (Robinson, 2014). This sampling approach is justified for this study from a pragmatic and feasibility perspective and is supported by a geographically specific sampling frame (Robinson, 2014). This strategy also aligns with calls for more engagement of older adults and family caregivers in research, healthcare decision-making and policy, as key underrepresented groups in these areas (Holroyd-Leduc et al., 2016).

Recruitment flyers were posted throughout the community (e.g. in supermarkets, churches, community centres, libraries and doctors’ offices), and e-mailed to various older adult groups. Interested participants contacted the primary researcher JG, who provided additional information about the study by telephone. Interviews were then scheduled at a convenient time and location/format (e.g. at home, by telephone) for participants. JG, a PhD student at the time of the study, with qualitative interview training, provided participants with a study information letter and obtained written consent prior to conducting the interviews.

2.2.3 | Approach

Solution-focused semi-structured key informant interviews were conducted with older adult home care clients and their caregivers. A semi-structured interview guide was developed according to the three discourses of a solution-focused approach and probed the following four key concepts of PFCC in relation to goal-setting in geriatric home care: (1) Dignity and Respect; (2) Information Sharing; (3) Participation; and (4) Collaboration (Institute for Patient- & Family-Centered Care, 2010) (see Box 1). Interviews lasted for 30–60 min.

**BOX 1 Sample interview guide for key informant interviews**

**Respect and dignity**

Can you tell me about a time when you felt that healthcare providers treated you with respect, listened to your input and acknowledged your choices?

[if yes]- What made this experience so great and how could providers consistently make this happen?

[if no]- What could providers do to make you feel like your input and choices are respected, acknowledged and incorporated into the care planning process? How do you think they should do this?

**Information sharing**

Can you tell me about a time when healthcare providers took the time to talk to you about your/ your family/friend’s needs and preferences for care?

[if yes]- What made this experience so great and how could providers consistently make this happen?

[if no]- What could providers do to make sure your needs and preferences are acknowledged and incorporated into the care planning process? How do you think they should do this?

**Participation**

Can you tell me about a time during your home care experience (as a client or caregiver) that you felt encouraged and supported in participating in goal-setting at a level you wanted to be?

[if yes]- What made this experience so great and how could providers consistently make this happen?

[if no]- How could providers encourage and support you and your family to participate in goal-setting at the level you would like?

**Collaboration**

Do you have any suggestions for how healthcare providers could better involve you in the care planning process? [e.g. asking questions about your unique needs, goal-setting, documenting your goals, etc.]
were conducted either with individual older adults or with older adult/caregiver dyads depending on the older adults’ preferences and were audio-recorded. JG kept a diary of detailed reflective notes following each participant interview to document any reflections, assumptions or initial interpretations of the conversations (Gale et al., 2013). Participants received a $25.00 CAD honorarium.

2.3 | Data analysis

Thematic data analysis was guided by the multi-step framework method described by Gale et al. (2013):

2.3.1 | Step 1: transcription

All audio-recorded interviews were transcribed verbatim. These transcripts, along with the reflective notes, were imported into NVivo 10 software for analysis (QSR International Pty Ltd, 2014).

2.3.2 | Step 2: familiarisation with the interviews

JG thoroughly reviewed each transcript and corresponding reflective notes. Additional memos were created in NVivo 10 (QSR International Pty Ltd, 2014) to document initial analytical impressions. This researcher then selected three representative transcripts for step 3.

2.3.3 | Step 3: coding

Two researchers (JG, PS) independently coded the three representative transcripts using an inductive open coding approach (Lofland et al., 2006; Pope et al., 2000). Line-by-line reading of each transcript was completed to identify important short phrases, sentences and passages (meaning units) and assign a label to classify them systematically (Gale et al., 2013) (see Table 1). Each researcher took reflective notes at this stage to document their impressions of the data and ideas about patterns across the three transcripts.

2.3.4 | Step 4: developing a working analytical framework

The two researchers (JG, PS) met to compare the labels they had assigned to the data and determine an agreed upon set of codes. Researchers categorised these codes inductively, and then deductively grouped these categories according to the four elements of PFCC that were explored in the interviews (Institute for Patient- & Family-Centered Care, 2010). A chart was developed demonstrating the relationship between codes, categories and elements of PFCC that formed the working analytical framework for the remainder of the analysis (see Table 2).

2.3.5 | Step 5: applying the analytical framework

JG applied the working analytical framework to code the remaining 17 transcripts using NVivo 10 software (QSR International Pty Ltd, 2014). Detailed reflexive notes were taken throughout this stage to track key impressions about the data in relation to the three discourses of a solution-focused approach.

2.3.6 | Step 6: charting the data into the framework matrix

JG developed four matrices to summarise the data for each category, with rows representing each interview (older adult or older adult/caregiver dyad).

| TABLE 1 Sample open coding scheme |
|-----------------------------------|
| Excerpt from transcript | Meaning unit | Label |
| ...and I keep adding new information. I stick stuff in the back and then they can read- Like, I told them about the wedding and when the grandbaby was born and that kind of stuff. So, they know they can talk to him about that sort of thing and the aphasia book is here all the time, but [name] doesn’t need to use it because she’s... Like, she- Like I said, she’s like one of our kids now. (laughs) And so, she knows probably more about the family than I do, but... (laughs) | I stick stuff in the back and then they can read-Like, I told them about the wedding and when the grandbaby was born and that kind of stuff. So, they know they can talk to him about that sort of thing | Personal history, family dynamics and background matter |
| Her skills to determine his mood for the day and his needs for the day, and, and meet that. Um, he talks nonstop about himself while she’s there, “And I used to do this, and I did that.” And she’s, “Oh, is that right?” And she gets him laughing. So she’s a mood changer right away. And then she sits down and has a coffee with me for 20 min, so it’s social. You know, and then she leaves. And um, I’ve never seen her anything but up and bubbly. | Her skills to determine his mood for the day and his needs for the day, and, and meet that. | Good communication and listening skills are essential |
2.3.7  |  Step 7: interpreting the data

Themes were generated from the matrices by comparing and contrasting data across participants and categories. The three discourses of a solution-focused approach were used to elaborate on each of the themes. Themes were shared and discussed with the second researcher to ensure they were consistent with the overall coding framework.

3  |  FINDINGS

Thirteen older adults and 12 family/friend caregivers were interviewed between July and October of 2017. Demographic data were collected from participants, based on known social factors influencing variation in home care experiences, including: age, rurality, gender, living arrangement and type of housing (Mah et al., 2021) (Table 4). Five interviews were with older adult/caregiver dyads. Our consideration and inclusion of the caregiver and care recipient as a dyad was the approach taken to accommodate various levels of client autonomy and caregiver involvement. All participants responded to the interview questions independently. Six of the caregivers interviewed were spouses, and six were adult daughters. Older adults were receiving home care services for a variety of complex health issues including stroke, multiple sclerosis, amyotrophic lateral sclerosis, muscular dystrophy, Parkinson’s disease, cancer and dementia.

Four themes emerged from the data: (1) seeing beyond age enables respect and dignity; (2) relational communication involves two-way information sharing; (3) doing ‘with’ instead of doing ‘for’ promotes participation; (4) collaboration is easier when older adults/caregivers lead the way (see Table 5).

3.1  |  Seeing beyond age enables respect and dignity

Older adults and their caregivers shared that respect and dignity would be better supported in home care if providers were able to see beyond age, when determining older adult goals and needs. Older adults and caregivers agreed that point-of-care providers need to make fewer ageist assumptions about older adults’ abilities to promote more active goal-setting. One older adult named Doris (all names used are pseudonyms) shared her belief that these ageist assumptions are based on physical appearance and numerical age: ‘Yes, it’s sort of, an assumption, you know? I mean, after all, it’s justifiable cause you look old (laughter). And you are old. But, um, it’s not as bad as they think.’ She shared that a more holistic view on ageing and goal-setting would reveal more opportunities in her care situation. Older adults also spoke about their desire to eliminate the often-patronising tone of conversations, tainted by assumptions about hearing, sight, cognition or care needs:

And not speak to senior citizens like they’re idiots, and don’t understand what’s going on. Um, being called “dear”. Uh ... I guess we’re just coming into this now,
there have been a few ages of things that I run into before, but somebody called me "dear" the other day, and I thought, "Oh, Lord. I have arrived." – Beatrice (older adult)

Older adults and caregivers alike believed that ageism could be reduced through focused goal-setting to protect older adult capacity and promote reactivation. One caregiver shared her experience with a complete lack of goal-setting when the planning team assumed that her husband would require institutional care:

And then they send somebody to check out your home. It- I, I found at the hospital, though, their first, their first ... Um, go-to reaction was, "What home are you gonna put him in?" And I’m going, "Oh. Well, I didn’t think he was that sick.” Like ... (laughs) You know, like, uh, it’s a stroke, yeah, but his whole right side was, um ... what they called 'weakened'. – Karen (caregiver)

Caregivers felt their inclusion in goal-setting would allow them to more accurately communicate realistic goals and ideas aligned with the preferences and abilities of the care recipient. A caregiver spoke about her husband’s experience after her advocacy:

He was able to enjoy his kids all summer. We were able to get away. And that’s the purpose of it. So he might have another year. He might have another five. But those one year or that five to be as good as could make it without judgment ... so the odd time I do, uh, I do get, uh, a caregiver...it’s your age, what the heck?

| TABLE 3 Sample matrix for ‘respect and dignity: ageist assumptions are dangerous’ |
|---------------------------------|---------------------------------|---------------------------------|
| **Janice**<sup>a</sup> (older adult) | Older adults grew up in a different era where you were very conservative about showing your body parts and having a stranger of the opposite sex bathe you requires them to be very professional<sup>b</sup> | Retirement home staff forget that we're adults and the poor excuses for lack of consistency in providers (e.g., so you don’t become too attached should you die) do not sit well with us | Nurse working on toenails causing chronic pain was going to give up saying: ‘I don’t think we are getting anywhere’, and older adult persisted and wanted to know step by step what other action could be taken |
| **Doris** (older adult) | The home PT wasn’t interested in the person; she was interested in physio and didn’t explain why she was giving certain exercises for certain parts of the body | Assumptions are made that because you look old you must be stupid, you must be deaf and you must be blind | A PT assessing pain in the foot offered no proactive help and the conversation was sparse, you have to live with it sort of thing |
| **Janet** (older adult) and **Alice** (caregiver) | Food modification recommendations were made only considering what parts of the body were not working properly which made her really not want to eat at all | Home care assessment questions seemed to be checking whether I had my marbles and asked if I knew what year I was born | Home care assessment questions seemed like they had already pre-determined that down the road, they wanted to get her into a nursing home |
| **Sue** (caregiver) | He has to be seen as the patient forever—all he's got really out of four appendages is his left arm and he's not naturally a left-handed person so this is difficult for him | Just because he has a speech disorder does not mean he does not want to communicate and he tries to say to them 'what's new?' and they will not engage and reply 'well, not much new' | ... for old people, it's, it's like, um... uh, it's like... do as little as possible, spend as little as possible. But for newborn babies, "Oh, wow." Yeah. You know. Like... (laughs) It’s... uh, uh, we can’t do too, we can’t do too much ever, ever, you know? |
| **Julia** (caregiver) | Contrasting the publicly funded palliative home care (it didn't seem to matter whether she could do the care that was required, it was just her body) with the privately funded care where the providers would give massages, use cold compresses, readjust pillows (they were totally aware of the process of death) | I wish they knew how extremely intelligent she was - several times the home support worker would talk to her like she was an imbecile | Older adult told caregiver - I just feel like they just want to stand me up against the wall and hose me down, and, and, uh, use a big hand blower and blow it all off me, and then throw me into bed |

<sup>a</sup>Pseudonyms have been used.

<sup>b</sup>Underlined text represents verbatim excerpts from transcripts.
You’re going to be gone soon, so I’m not going to help... we’ll get that, you know. And then they get mother bear coming out of her cave, you know, sort of thing. – Hazel (caregiver)

According to this participant, a proactive approach should become usual practice and not require constant advocacy by caregivers. To decrease ageism and foster more proactive goal-setting, participants felt that point-of-care providers would need to talk ‘with’ older adults and caregivers instead of ‘at’ them. One older adult shared his positive experience of goal-setting when point-of-care providers used conversational care planning:

So, that’s one of the key things that, honestly, I would give them 100% because in fact they wanted to know what are my choices and why are those choices important and so on. Uh, that’s very important for the individual. It’s not to say, "This is what we deliver. If you like it, you can take it. If not, tough bananas." Um, it’s not... healthcare is not about that. Healthcare is about the individual. Uh, and you have to come to understand that by taking that history and then sharing it. – Joe (older adult)

He and his caregiver felt very strongly that this interactive dialogue allowed point-of-care providers to see beyond his age, treat him as an individual with capabilities, and define corresponding goals.

### 3.2 | Relational communication involves two-way information sharing

Older adults and caregivers stressed the importance and need for two-way information sharing to establish a pattern of communication between older adults and point-of-care providers that would support relationship-building and goal-oriented care. One caregiver named John shared his frustrating experience trying to engage point-of-care providers in this manner: ‘Um... they suffer from at least one major problem, and from my perspective, it’s highly important. That is, they do not communicate, or if you attempt to communicate, I get the feeling you’re being ignored’. Older adults and caregivers agreed that point-of-care providers needed to make substantial changes in knowing and using personal history, needs and background information in care planning. An older adult talked about care providers respecting his desire to read once they knew about his previous profession:

Uh, sometimes they do. We’ll- We’ll talk and they’ll ask me questions about my previous work. I was a reporter and photographer with, uh, the old [name] newspaper office here. I was there for 12 years, and, I guess, that’s where I... No, I always liked books. And, uh, they sometimes ask me about- about my work at the [newspaper office] – Jack (older adult)

In terms of a solution to realise this change, older adults talked about providers having a more holistic view of the care situation. One caregiver had worked as a personal support worker prior to retirement

### TABLE 4 Key informant interview participant characteristics

| Characteristics | Older adults (n = 13) | Family/friend caregivers (n = 12) |
|-----------------|----------------------|-----------------------------------|
| Area            |                      |                                   |
| Rural           | 1                    | 2                                 |
| Urban           | 12                   | 10                                |
| Age group (years) |                     |                                   |
| 55–65           | 0                    | 10                                |
| 65–75           | 5                    | 1                                 |
| 75–85           | 4                    | 1                                 |
| 85+             | 4                    | 0                                 |
| Gender          |                      |                                   |
| Male            | 4                    | 1                                 |
| Female          | 9                    | 11                                |
| Living Arrangements |                  |                                   |
| Alone           | 8                    |                                    |
| With someone else | 5                  |                                    |
| Housing         |                      |                                   |
| Detached house  | 6                    |                                    |
| Apartment building | 4                |                                    |
| Retirement home | 3                    |                                    |

### TABLE 5 Solution-focused themes for improving person- and family-centred goal-setting in geriatric home care

| Theme                      | Seeing beyond age enables respect and dignity | Relational communication involves two-way information sharing | Doing ‘with’ instead of doing ‘for’ promotes participation | Collaboration is easier when older adults/caregivers lead the way |
|----------------------------|------------------------------------------------|-------------------------------------------------------------|----------------------------------------------------------|---------------------------------------------------------------|
| Change                     | Decrease ageism around sight, hearing, cognition and care needs | Increase awareness of personal history, needs and background | Make fewer assumptions that ageing in place means being sedentary | Increase opportunities to direct the care environment |
| Solution                   | Focus on older adult capacity and reactivation | Uncover a holistic picture of the care situation | Support older adults to be as independent as possible | Actively engage in shared decision-making |
| Strategy                   | Talk with and not at older adults/ caregivers | Build trust and understanding | Trust older adults/caregivers to know their limits | Tailor care activities based on preferences that matter |
and described how to build relational communication through information sharing:

And, kind of, as time went on if I was with the same person, uh, I would like ... there'd be time to, kind of, form some type of a relationship with them and- and it was more of a one-on-one basis and so ... We would talk. They would tell me things, and- and I would, sort of, take that back with me and- and put it up here.-- Penny (caregiver)

Another caregiver recommended that point-of-care providers use a personal biography sheet to record and share information to support a holistic approach:

Oh, God. Wouldn't that be wonderful? A little bio sheet, okay. What did this man do for a living? How many children does he have? Does he have grandchildren? Where were you born? Do you speak two languages? What are your skills? You have hobbies? What religion are you? Are you religious?—  Hazel (caregiver)

According to older adults and their caregivers, a key strategy for uncovering a holistic picture of care requires building trust and understanding:

And, uh, it's like, a bit of a bonding like, you know, that, uh, you'll ask them how their children are and, when you've had a blood test or something, they'll say, how did that go or something, you know? - Janice (older adult)

A caregiver talked about this type of bonding between her husband and his care providers:

So it's, um, I glimpse into what my husband, like, some of the workers are really good, and they'll, they visit with him as they're doing their work. And, uh, and I hear a laughter coming from the bedroom when they're, you know, getting him ready for breakfast and that kind of thing and, or, you know, tell about their family or a holiday or experience, and they really engage with him. - Sue (caregiver)

This caregiver felt relational communication puts everyone at ease in the care planning situation, and brings humanity and reality into the goal-setting process through balancing clinical and non-clinical information sharing.

3.3 | Doing ‘with’ instead of doing ‘for’ promotes participation

Older adults and caregivers expressed their ideas about care planning being more participatory if point-of-care providers do care activities ‘with’ rather than ‘for’ older adults. One older adult, Lois, expressed her attempts to be more independent in her bath routine: 'Like they’ll bath me if I want them to bath me, but I, usually don't, I usually like to do it myself...But I ask them to stay just in case I fall or something. In the bathtub'. According to participants, a key change to support more participatory care would be for providers not to assume that ageing at home means becoming completely dependent. One older adult shared her experience of requesting assistance and being met with a suggestion to have someone do the activity on her behalf instead:

And I said was there ever, was there any way that I could have somebody help me with my grocery shopping? And he said 'Oh, yes, you, they have this, uh, you give them a list and they go out and shop and they bring it back and, uh, you pay for it.' But, that's not helping with my grocery shopping, that is just grocery shopping. -Doris (older adult)

Older adults and caregivers felt that participatory goal-setting in geriatric home care would allow point-of-care providers to support older adults and caregivers to be as independent as possible. One older adult named Janet discussed her desire for more dialogue in the re-assessment process she undergoes every 6 months with her home care provider, sharing that there is an assumption made that they will continue to bathe her and make her bed regardless of changes in her needs or preferences: 'No, they don’t ask how I am, is there anything I would like, but just that they know that I get washed and the bed made. And they emphasise the sponge bath, and I said, “Yes, I know, I do not have a shower.”' Participants felt that a strategy for achieving more participatory goal-setting would be for providers to trust older adult and caregiver opinions and understanding of their own limits:

Although, in some ways, they limit what I want to do. Like I get into the bath, I say, "Let me sit down and put my legs in myself." That's going to take some training, because they want to do it. That type of thing...Cause they're afraid I'll fall, whereas I'm the one that knows whether my balance is good or not. -Gail (older adult)

A caregiver also shared her experience in listening to a point-of-care provider’s advice against her own judgment and the poor outcome it led to:

An occupational therapist came in and said, “You're pretty wobbly on your feet. You really should have a walker.” Because he was, a little, you know, he's got a cane. So all right, [name] gets the walker. Well, it's been horrible. Because you start walking bent over, and he's so bent over now he can't stand up straight. And even his neck is down like this, so he has to go like this, all from the walker. -Hazel (caregiver)
This caregiver felt that had she been heard, her husband could have continued to use his cane and rebuild his walking ability with participatory rehabilitation.

3.4 | Collaboration is easier when older adults and caregivers lead the way

Participants discussed the reality that in a home-care setting, collaboration with point-of-care providers is easier when older adults and caregivers lead the way. One caregiver expressed her desire for providers to accommodate her priorities as a result of her more dominant role in care:

The priorities here are to just get through a day and put a decent meal on the table once a day and meet his needs because, um, I don’t know that they ever stop to think that, you know, “She’s here, uh, 21 hours a day with no help. We’re only here three hours a day,” and, um, you know, if he needs help through the night, guess who’s it, you know? I am.

–Sue (caregiver)

According to participants, providers should recognise the right of older adults and caregivers to direct the care environment in their own homes. One older adult discussed this:

Yeah, I know. The one I have, she’s a person that really ... The warmth affects her a lot. She sweats a lot, so she’ll come in the house, and I’m the one that needs it warmer, she’ll just open all the windows. And I’ve told her several times, “It’s my house. I will tell you.” Now I did have that into her head, (laughs) now she’s starting to do it again.

–Gail (older adult)

Participants shared that more collaboration in geriatric home care planning would involve shared decision-making. For example, one older adult discussed a decision not to undergo suggested treatment after planning would involve shared decision-making. For example, one older adult discussed this:

“I don’t wanna take the last thing ...” That’s the last thing she has, and I … I don’t wanna kill her with it, but I’ve taken everything from my ... in my mom’s eyes, I’ve taken everything.

–Margaret (caregiver)

Another caregiver described an ideal approach to a smoking cessation plan for her mother who had unique needs due to dementia:

So, I said, "That’s not an option, but instead of smoking two cartons in a month, can we cut it down to one? Can we at least try to figure out something? I don’t want a miracle. I don’t wanna take the last thing ...” That’s the last thing she has, and I ... I don’t wanna kill her with it, but I’ve taken everything from my ... in my mom’s eyes, I’ve taken everything.

–Hazel (caregiver)

This caregiver strongly commended the provider for open-mindedness and flexibility to meet the needs of the unique care situation.

4 | DISCUSSION

Older adults and their caregivers shared a range of ideas for improving person- and family-centred goal-setting in geriatric home care based on their lived experiences. Participants identified that seeing beyond age, relational communication, doing ‘with’ instead of doing ‘for’, and collaboration were key enabling factors of respect and dignity, information sharing, participation and collaboration in the care planning process. Older adults and caregivers want to be actively engaged in dialogue during care planning to ensure that their preferences, needs and personal history are applied in designing a care plan that promotes their participation at a level they choose and that is conducive to their personal environment.

Ageist stereotypes and discrimination against older adults have been cited as significant barriers to health equity in terms of the quantity, quality and outcomes of care (Wyman et al., 2018). During the COVID-19 pandemic, ageism and a public discourse of vulnerability and dependency of older adults, were shown to have a negative impact on older adults’ life satisfaction and subjective health (Barth et al., 2021; Kornadt et al., 2021). Ageism can take place at different levels in the healthcare system, with micro (personal) level ageism involving the attitudes of individual providers, ageist communication styles and decision-making about care and macro (system) level ageism involving healthcare funding structures, policies and training of professionals (Wyman et al., 2018). At the micro level, ageist communication can emerge across disciplines due to limited provider self-awareness, gravitation towards the simplest options and not being able to relate to older adults as individuals (Ben-Harush et al., 2017). Creating time and space for point-of-care providers to spend more time in dialogue with older adults and their
caregivers would help to address some of the micro level challenges with ageism in home care in a practical way.

Relational communication builds empathy for older adults’ unique care situations and incorporates this empathy into care planning (Eton et al., 2017; Mercer et al., 2004). Key components of relational communication between patients and providers include: mutual trust, preparedness to communicate, emotional support and a shared vision (Peltola et al., 2018). Related actions include active listening, eye-contact, clear explanations and taking interest in someone’s whole story (Eton et al., 2017; Mercer et al., 2004). Relational communication has been shown to enhance patient self-management ability and improve therapeutic relationships (Eton et al., 2017; Mercer et al., 2004). These findings are aligned with the results of this study that building trust and understanding among providers, older adults and caregivers is key for providers to acquire increased awareness of personal needs, history and background.

Promoting increased independence and restorative care in home care provision can help older adults gain, retain, or regain skills needed to function in their everyday lives as independently as possible and to increase quality of life (Aspinal et al., 2016; Tessier et al., 2016). While principles of reablement are well defined, the practices of mutual goal-setting and designing and delivering customised care activities to support self-defined goal achievement, physical independence and social connectedness have been largely unrealised (Clotworthy et al., 2021; Legg et al., 2016). The current study suggests that a starting point for achieving a reablement approach in home care could be equipping point-of-care providers to ask more questions during the goal-setting process, so they make fewer assumptions about the sedentary nature of older adults and promote independence in planning care activities that consider older adults’ and caregivers’ perceived abilities and limitations.

Enhanced collaboration between older adults, caregivers and healthcare providers has been recommended in literature exploring their experiences delivering and receiving care (Giosa et al., 2014; Stolee et al., 2019; Toscan et al., 2012; Toscan et al., 2013), yet few studies have explored the specific activities required by point-of-care providers to support this outcome. Evidence from recent exploration into patient and provider perspectives on patient-centred goal setting in geriatric rehabilitation revealed beliefs from providers that older adults are unable to generate realistic goals (van Seben et al., 2019). Another qualitative study found that there is great disparity between providers’ and older adults'/caregivers’ impressions of their collaboration in the care planning process, with providers citing much higher perceived collaboration (Ploeg et al., 2017). These researchers recommended that providers should apply person- and family-centred approaches that involve ‘listening to and acting on the voices of older adults and family members’ (Ploeg et al., 2017, p. 13). The findings of the present study suggest that providers can facilitate enhanced collaboration through a dialogue-based approach that encourages older adults and caregivers to direct and control the care environment and participate in shared decision-making; thus, alleviating tensions in current goal-setting practices and supporting individualised care activities based on preferences and needs.

4.1 | Strengths

Strengths of this qualitative study include the use of a solution-focused approach to actively engage older adults and caregivers in developing ideas for change, extending current knowledge beyond documenting older adults’ and caregivers’ experiences. Another strength is that the emergent solutions are rooted in lived experiences of the current healthcare system, and therefore may be more realistic, feasible and likely to influence positive change.

4.2 | Limitations

Generalisability of study findings may be limited as participants represented a convenience sample of home care recipients in only one of the 14 LHINs in Ontario. However, the heterogeneous nature of the sample of participants representing a broad range of ages, health concerns, urban and rural dwellings and caring relationships, supported achieving saturation. Race and ethnicity data were not collected from participants, which is a limitation in fully understanding the diversity of the sample. We recognise that the findings do not reflect the full range of individual older adult and caregiver experiences.

5 | CONCLUSIONS

According to participants, person- and family-centred goal-setting would be better supported by providers who take time to see beyond age, engage in relational communication, facilitate participatory goal-setting and collaborate more effectively. The solutions suggested by older adults and caregivers in this study are consistent with recommendations for applying person- and family-centred care in recent literature and extend current knowledge by offering action-oriented strategies that can be tested in geriatric home care goal-setting practice.

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CONFLICT OF INTEREST

Authors JG, KB and PS have no conflicts of interest to declare.

ETHICS

This study received ethics clearance from the University of Waterloo Office of Research Ethics (ORE #22251).
DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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