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"You're Part of Us and We're Happy to Have You Here": Practices of Social Inclusion for Persons with Dementia

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ABSTRACT

Objectives: Practices of social inclusion are important for maintaining the relationships of persons with dementia and are associated with positive clinical outcomes. The objective of this study was to explore the in-action practices of social inclusion in the activity center of a community-based organization.

Methods: This study applies an ethnographic approach – including participant observation, informal and semi-structured interviews – with persons with dementia (n = 31) and organization staff members (n = 9) to explore the in-action practices of social inclusion.

Results: Seven in-action practices of inclusion were identified: ensuring time for individual relationships, building schedules centered around flexibility, empowering decision-making, normalizing dementia-related behaviors, involving family members, soliciting and integrating persons with dementia's feedback, and supporting persons with dementia to practice social inclusion.

Conclusions: Care providers of individuals with dementia can effectively facilitate active connections with them by continually soliciting and incorporating their feedback, and by supporting persons with dementia to practice inclusion and care for others.

Clinical Implications: Community-based organizations can be effective at supporting the active connection of individuals with dementia with others and should be promoted for individuals with mild to moderate dementia.

Introduction

The progression of dementia is often accompanied by a fracturing of proximal and distal relationships, fraying the social inclusion of individuals living with this condition. The recent shift from person-centered care to relationship-centered care (de Witt & Fortune, 2019) reflects the growing effort to ameliorate this decline, as higher levels of social inclusion have been associated with lower levels of depression, and higher self-esteem and quality of life of persons with dementia and their caregivers (Leung, Orrell, & Orgeta, 2015). While social inclusion has been widely conceptualized as a multidimensional phenomenon with social, psychological and physical components (e.g. Labonte, 2004; Prince, & Gerber, 2005), our study focuses upon a specific variant of social inclusion, namely, the active connection of individuals with dementia with others. In other words, we have chosen to understand social inclusion as a situated experience (O'Sullivan, Bryant, & Hewett, 2016) of meaningful involvement with another person, group or environment, which provides comfort, wellbeing and sense of belonging (Taket et al., 2009; Townsend, & McWhirter, 2005).

This study presents a set of in-action practices of social inclusion that are situated, responsive, and negotiated in the context of a community-based organization for individuals with dementia and their carers. Our focus on "in-action" practices refers in part to Schön's notion of how knowledge is tacit in action (Schön, 1983) and draws from pragmatic theories of social behavior to indicate practices that are actually used by agents (Gross, 2009). Within these theories, understanding the subjective and intersubjective

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dimensions of actions is paramount since the meaning attributed to behaviors varies according to the individual and since these dimensions are inherently part of practices. In-action practices can be contrasted to non-applied recommended practices as well as strategies that describe human behaviors from the third person standpoint without trying to understand their subjective and intersubjective dimensions. By focusing upon actions, which are imbued by the meaningfulness to and intended purpose of the agent, our intent is to extend the research lens to capture the various ways in which social inclusion is pragmatically enacted. In the context of dementia, this approach has only been taken in a handful of studies (Fortune & McKeown, 2016; Hare, 2016; Williams, 2013).

The overall objectives of this study were: 1) to illuminate the in-action practices of social inclusion provided by institutional carers that were responsive and negotiated in the context of a community-based organization for persons with dementia; 2) to understand how these enacted practices of active connection were experienced by persons with dementia; and 3) compare such practices with the existing literature, highlighting those that are less discussed in studies on person-centered care.

Methods

Setting

This study focused on the in-action practices of social inclusion implemented by one community-based organization, Alzheimer's Group Inc (AGI). AGI (henceforth referred to as "the community organization") is a charitable organization in Montreal, Canada that offered therapeutic programs to persons with dementia and provided support services to families and professional care partners. Most of AGI's clients came from the surrounding neighborhoods. Selection criteria to become a member of the activity center did not exist, but there was often a waiting list due to the high demand. The Aisenstadt Activity Center at AGI was a day program where persons with dementia socialized and performed meaningful activities (see Harmer & Orrell, 2008 on meaningful activities), which were defined in concert between staff and clients. As stated by other studies, what made these activities meaningful were factors such as their relationship with past roles, interest and routines of persons with dementia as well as their potential for reinforcing personal identity, fostering enjoyment and sense of belonging (Harmer & Orrell, 2008). The Aisenstadt Activity Center followed a person-centered care approach, a widely accepted value-based commitment to supporting persons with dementia, and a guiding principle used internationally in care services (Fazio, Pace, Flinner, & Kallmyer, 2018; Kitwood, 1997; Manthorpe & Samsi, 2016). The activities of the center were created and delivered by a team trained in person-centered dementia care. To target the specific needs of the diverse persons with dementia, the interdisciplinary team included recreational therapists, art therapists, music specialists and social workers, as well as students and volunteers.

Data collection

We conducted an ethnography to explore the practices of social inclusion implemented at AGI's activity center from the points of view of the different actors involved in their enactment (Geertz, 1973). This approach was particularly suited to persons with dementia, as it created a sustained period of time to form social relations and meaningful engagement with the participants, and to study them in familiar settings where they conducted their everyday activities (Antelius, Kiwi, Strandroos, Kiwi, & Strandroos, 2017; Ludwin & Capstick, 2016). Forty participants (n = 31 persons with dementia; n = 9 staff members) were recruited through purposive sampling (Emmel, 2013). The demographics of all participants are presented in Table 1. Those with dementia were at different stages of progression: most had mild and moderate dementia, and all were socially responsive to staff and researchers. We ensured safe and inclusive research practices for this population by not using stage of dementia as an inclusion criteria, but by involving all who expressed willingness to be part of the study (Novek & Wilkinson, 2019). Staff members had an average of 11 years of experience working with individuals with dementia. The study was approved by the Institutional Review Board of McGill University. Written consent was obtained

Table 1. Demographics.

Participants	#	Age		Sex		Languages spoken[a]								Ethnicity[b]		
		Mean	Range	F	M	E	F	Y	H	R	P	I	OL	J	EC	OE
Persons with dementia	31	83.4	71–94	17	20	31	23	12	4	3	3	3	5	20	5	6
Staff members	9	40.6	30–56	9	1	9	8	1	1	1	0	0	2	1	3	4

[a] E = English, F = French, Y = Yiddish, H = Hebrew, R = Russian, P = Polish, I = Italian, OL = Other languages (Arabic, Czech, German, Turkish, Spanish, Romanian, Hung and Tagalog)

[b] J = Jew, EC = English Canadian, OE = Other ethnocultural background (French Canadian, Caribbean Canadian, Italian/Italian Canadian, American Canadian, Filipino, German, Romanian, Welsh, West African, Iraqi)

from all staff members and caregivers, and primary caregivers consented on behalf of persons with dementia. To making consent a meaningful research activity where persons with dementia could participate to the level of their abilities, regardless of legal capacity, verbal assent was sought from all persons with dementia prior to and throughout the course of the study (Dewing, 2008).

Over a 9-month period, the first author spent 220 hours in participant observations and informal interviews while accompanying persons with dementia in their activities at community organization (e.g. playing card games and memory games, dancing, doing tai chi, drawing and painting) and supporting staff members in non-therapeutic practices (e.g. setting tables, distributing food, helping clients). Additionally, a sub-group of individuals with dementia (n = 6) and staff members (n = 7) were selected through purposive sampling to participate in semi-structured interviews, conducted by the first author in English and French to discuss their experiences of social inclusion. Examples of interview questions for individuals with dementia include "What do the staff members do to make you feel comfortable/good/that you are part of/that you belong to the activity center?", and "Could you tell me about a moment or situation in which they make you feel comfortable/good/that you are part of/that you belong to the activity center?"; examples of questions for the staff include "What do you do to make the clients feel socially included at the activity center?" Interviews were conducted the last two months of the study, after developing a relationship of trust with the participants and knowing them enough to adapt the interview questions to their specific conditions (Digby, Lee, & Williams, 2016; Hubbard, Downs, & Tester, 2003). To ensure sample diversification (Pires, 1997),

additional criteria including gender and age were considered and diversified. Interviews of persons with dementia occurred either alone or in dyads (when they required the support of their caregiver) and ranged from 15– 90 minutes. We allowed people with dementia to choose the time, duration and place of the interviews (Hubbard et al., 2003; McKillop & Wilkinson, 2004; Scottish Dementia Working Group, 2014). Interviews were conducted in locations familiar to the participants (e.g. homes and Aisenstadt Activity Center). We gave them the option of stopping the interview at any time and doing it in multiple sessions (Nygård, 2006). Staff members from AGI helped the researchers tailor the interview to the specific needs of each person with dementia.

Throughout data collection, while observations and informal interviews were steered toward the topic of social inclusion, we allowed participants to define and reinterpret the topic in ways that were most meaningful to them. Participants interpreted questions of social inclusion as questions of comfort, feeling good, feeling part of, and belonging. In academic discourse, the concepts that social inclusion (and exclusion) circumscribe are contested, imprecise and often ambiguous (Rawal, 2008; Taket et al., 2009), ranging from satisfaction of basic needs (C. Lloyd, Tse, & Deane, 2006), to having opportunities to participate in society and to enact rights of citizenship (e.g. (Bartlett & O'Connor, 2010; Levitas et al., 2007). We reconcile these academic discourses with the participant's interpretation of inclusion by taking a narrow, more specific lens on actions that enabled the active connection of individuals with dementia to activities and to others. While this resembles social inclusion, it is the particular facet of this multi-dimension phenomenon that resonated with the participants of this study.

Data analysis

Fieldnotes of participant observations and recordings of semi-structured interviews were digitally transcribed and imported into NVivo 11 software to support analysis. Data was anonymized by changing names of participants, institutions and sites. The first author analyzed the data using an emergent approach, in which she did not use predetermined categories, but let the categories emerge from on-the-ground qualitative research (Miles, Huberman, & Saldana, 2014). Categories and subcategories were discussed with the research team in face-to-face meetings until discrepancies were resolved and consensus was achieved. Two community-based partners from AGI (MW, PB) were involved in the group meetings, reviewing the codebook to validate the relevance of emergent categories and subcategories, and providing their insight for interpreting the findings. The first author then conducted a thematic analysis of all collected data, with four other members of the research team analyzing 20% of the information to ensure reliability (Miles et al., 2014). Throughout the analysis, fieldnotes and semi-structured interviews were comparatively analyzed for triangulation. We present each theme using illustrative quotations, which were edited for clarity and translated into English when necessary.

Results

A list of the pragmatic in-action practices of social inclusion at the community organization is presented in Table 2. Although all the emergent practices were staff-initiated, we only included those which were identified as meaningful by both staff *and* individuals with dementia. In what follows, we will describe these in-action practices and how they are situated, responsive, and negotiated in the context of a community-based organization for individuals with dementia. We will start by presenting the practices of social inclusion linked to recommendations for person-centered care that are frequently discussed in the literature: ensuring time for individualized relationships; building individualized activity schedules centered around flexibility; empowering decision making; normalizing dementia-related behaviors; and involving family members. We will then present our original findings about practices of social inclusion: soliciting and integrating feedback of persons with dementia and supporting persons with dementia to practice social inclusion and care for others.

A. Ensuring time for individualized relationships

A widely accepted principle in person-centered dementia care – and a frequent critique of more traditional dementia care – is that staff need to have sufficient time to form, nurture, and maintain individualized relationships with persons with dementia (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018; Levy-Storms, 2013). At the community organization, this principle is enacted by keeping provider-client ratios low. According to staff members, having the time for individualized relationships fostered social inclusion: "If you have the time to build a relationship of trust with your client, you know what he likes, what he doesn't and you know how to make him part of the group." On their side, persons with dementia enjoyed spending time and having individualized relationships with staff members.

> I don't know how they do it, but they make time for each of us and this is fantastic ... They stay with us, spend time with us and get to know us better. They know I'm diabetic; they give me sugar free cookies ... I like word games and singing certain songs and they remember ... This makes me feel good! (Homer, person with dementia, semi-structured interview)

Additionally, developing individualized relationships requires that people with dementia spend time with consistent and stable staff. As pointed out by Angela: "[people with dementia] forget and for us, it is nice to see the same people." Although studies have shown that time constraints are one of the major barriers to implementing person-centered care (e.g. Lloyd, Elkins, & Innes, 2018; Moore et al., 2017) and social inclusion (e.g. Rodriguez et al., 2003), one staff member suggested that even spending "quality time here and there with clients" cultivated personalized relationships and had a significant impact on their "well-being" and sense of belonging.

Table 2. In-action practices of social inclusion.

Practices of social inclusion	Description	Data sample
Ensuring time for individualized relationships	Individualized relationships that foster social inclusion demand time from staff that should be ensured.	"I don't know how they do it, but they make time for each of us and this is fantastic … "
Building schedules centered around flexibility	Flexible programing is crucial to incorporate the individual needs and preferences of persons with dementia, which promote their social inclusion.	"Why don't we change the program and start with a singing activity?"
Empowering decision-making	Decision-making that validates people with dementia and engenders social inclusion	"You can't ask some clients, Which activity do you prefer to do today?' They might say 'whatever you prefer.' Too much to think about.'"
Normalizing dementia-related behaviors	Normalization and acceptance of dementia- related behavior foster social inclusion and allow persons with dementia to socially include others.	"When a peer was like, 'Why is she doing that? That's not okay', we would validate those feelings, but also normalize the behavior."
Involving family members	Family members as care partners help to promote social inclusion of persons with dementia.	"I think that for families, too, there is the concern of "How are you gonna see my wife? Are you gonna see her as a sick person?'"
Soliciting and integrating persons with dementia's feedback	Integration of persons with dementia's feedback and criticism in the activity program foster social inclusion.	Before leaving, Betsy approaches Michelle and thanks her for incorporating her feedback.
Supporting persons with dementia to practice social inclusion	Persons with dementia care for others and perform acts to socially include them.	She comes back to me and tells me she loves to look after others.

B. Building individualized activity schedules centered around flexibility

Staff members adapted the environment, activities, social interactions and therapeutic approaches to the individual preferences and needs of each person with dementia, which demanded a high degree of flexibility. Staff met daily to collectively create a program tailored to the persons with dementia who were expected to come that day. However, as staff members often said, the program was only a "guide" and they will "take it as it comes", "go with the flow", or "play it by ear".

> Patricia tells Ariel and me that Eve is coming today. This is unexpected. The day that Eve usually comes, staff

members plan a calculus activity because she is a mathematician. Today, the art therapist is coming and Eve does not like art. Patricia and Ariel deliberate and then Patricia proposes: "Why don't we change the program and start with a singing activity? After that we can dance and then I will motivate her to engage in art. If I am not able to, I will do something else with her and you will be in charge of the group." Ariel agrees. Eve arrives with her caregiver. Patricia asks everybody: "Who likes Elvis? We are going to play some Elvis songs" Eve raises her hand and begins singing "Can't help falling in love". Patricia stays with Eve and sings the songs with her, while the others dance. Between songs, they chat. Meanwhile, Rebecca, the art therapist, is in the other room preparing materials for the art activity. Patricia invites Eve to do some art and tells her that they can continue singing while doing art. Eve agrees. After the program, Patricia is uncertain if Eve is going to return. However, a few hours later, Eve's caregiver calls to let the staff know that Eve really enjoyed the program and that she is coming back next week. (Participant observation)

Staff members pointed out that there is not a specific way to make the program socially inclusive, but that the general rule was to have the flexibility to improvise and change the activity schedule, such as when Patricia changed her plans last-minute to incorporate one of Eve's favorite activities. However, not all persons with dementia at the community organization were "people persons" and needed to be social all the time. For some persons, "too much inclusion" in the group was experienced as social exclusion (Motta-Ochoa et al., 2021). Staff members had to give these persons time and separate spaces where they could be on their own and do individual activities.

C. Empowering decision-making

Although staff members were aware that dementia can progressively affect the decision-making abilities of persons with dementia, they tried to ensure that persons with dementia made their own decisions for as long as possible by focusing on "one decision at a time." They believed that decision-making fostered feelings of enjoyment and social inclusion. To support the person with dementia's decision-making process, staff adapted to his/her cognitive skills through strategies such as using simple and clear language, supporting verbal statements with visual material and limiting the number of options.

Alice moves outside the group and sits alone in a chair. Shirley approaches Alice, shows her a deck of cards and a pastel box, and asks if she wants to play cards or if she prefers to do art. Alice points out toward the deck of cards. She joins two other persons with dementia and starts playing "Crazy 8s". Alice laughs and enjoys the game. Afterwards Shirley explains that sometimes it is difficult for the person with dementia to make decisions: "You can't ask some clients, 'Do you wanna do an activity? Which activity do you prefer to do today?' They might say 'none,' they might say 'whatever you prefer.' Too much to think about. It is easier for them to say, 'I don't want to do anything.' But if you give them options, 'Do you want to do art or to play cards?' They can choose, they feel in control and they are more engaged in the activity.„ (Participant observation)

However, as dementia progresses, it becomes increasingly challenging for persons with dementia to make their own decisions. In the case of persons who had limited verbal communication abilities, staff members used previously collected information about preferences and needs to tailor their participation in specific activities, maintaining their inclusion in the group.

D. Normalizing dementia-related behaviors

Certain behaviors associated with dementia – often called BPSD (behavioral and psychological symptoms in dementia) – such as agitation, restlessness, poor control of emotions, but also incontinence and repetitive speech are stigmatized in most social settings and are at the root of the social exclusion experienced by persons with dementia and their caregivers. In some environments, such behaviors are heavily medicalized, although many researchers have shown that at least some behavioral and psychological problems can be successfully approached through non-drug interventions (e.g. Caspar, Davis, Douziech, & Scott, 2018). Staff members at the community organization constantly tried to normalize these behaviors. Normalizing here does not mean to ignore or to banalize symptoms – they can be signs of distress and underlying disease. However, accepting symptoms as "part of life" – by "un-othering" symptoms – engendered feelings of acceptance among persons with dementia (Cryle & Stephens, 2017). Although they occasionally felt annoyed for the disruptions of some of these behaviors, they understood that they were part of

the progression of dementia and appreciated the ways in which the staff accommodated them.

> This staff here is very warm, and accommodating, and understanding . . . they accept whatever we offer and when [they] correct us, [they] do it in a very pleasant and acceptable way. . . . Some of the [other clients] open up a little bit too loud, but then they calm down, you know? [The staff] know how to calm them down and they [the clients] don't even know they're being calmed down. Which is a knack. (Natalie, person with dementia, semi-structured interview)

The staff deliberately addressed BPSD that arose in group settings, normalizing these behaviors to foster inclusion and engender compassion in their clients.

> [When she got into the group] her boundaries were falling apart. She couldn't contain a lot of her emotions and actions. She was really hypersensitive to sounds, and smells, and movement. So, we got another staff in, constantly shadowing her, and we had to normalize things that were happening that were really unusual for other people . . . Also, it helped other people practice inclusion. When a peer was like, "Why is she doing that? That's not okay", we would validate those feelings, but also normalize the behavior and see if it allowed opportunities to talk about other things, like difficulties someone might be having. And sometimes that's fostering other aspects of themselves that are not being fostered, where they get to be the compassionate person or the caregiver, the person who is adapting to someone who is having more trouble than them. (Pamela, staff member, semi-structured interview)

As pointed out by Pamela in the interview excerpt, persons with dementia themselves also normalized these behaviors in their peers. In doing so, persons with dementia assumed care-flipped roles: they became the caregivers of someone who experienced more problems than them and fostered his/her social inclusion.

E. Involving family members

Whenever possible, staff members involved family members in shaping therapeutic programs and interventions for their loved ones. Family members provided key information about the person with dementia, helping staff members make choices that would benefit them. If family members wanted to see how their loved ones were treated or if the person with dementia was having a hard time

adjusting to the group, family members were welcome to stay during the program.

> It was also about involving her husband, her husband building a relationship with me, and seeing how I interacted with his wife. I think that for families, too, there is the concern of "How are you gonna see my wife? Are you gonna see her as a sick person? Are you gonna interact with her as though she has these huge limitations?" (Pamela, staff member, semi-structured interview)

Persons with dementia appreciated the staff's disposition to integrate family members and caregivers into their programs. In an informal interview, Luke told us that he liked that his wife was aware of what he did in the community organization because this way she knew he kept active and "[didn't] lose [his] time." As a staff member pointed out, persons with dementia proudly shared what they do at the community organization with their caregivers to show that they were able to perform meaningful activities and that they were part of a social group that valued them.

F. Soliciting and integrating the feedback of persons with dementia

Staff actively gathered and incorporated the feedback and criticism of persons with dementia to improve the activities and therapeutic approaches. This not only validated the person with dementia's ability to contribute to the program and positively impacted their self-esteem, but also were experienced as social inclusion, as exemplified by Betsy in the following fieldnote excerpt:

> A week ago, Betsy - a relatively new client and a former history teacher - told the staff that she tended to be critical and that she found the group conversations too superficial. Today, Michelle starts the day saying: "Betsy has told me she is very critical and I'm going to incorporate her criticism." Then, Michelle proposes a writing activity to commemorate Nelson Mandela Day, which was coming soon. She asks everybody to reflect on the question "What does freedom mean for me?" and subsequently to write her/his reflections down on a piece of paper. After everybody finishes writing, Michelle asks each of the persons to read aloud what they wrote or to share their opinion. All of them were engaged in an interesting discussion about freedom that extended for almost 40 minutes. Before leaving, Betsy approaches Michelle and thanks her for incorporating her feedback: "This has improved the level of our conversation and made me feel part of the group." (Participant observation)

In addition, feedback from people with dementia was often solicited at the end of each session by simple questions such as "how could we improve the program?" or "what would you like to do next week?" According to staff members, this practice empowered persons with dementia, supporting the feeling that they belonged to a group in which their opinion mattered. Moreover, the opinions of persons with dementia enriched the staff interventions and enabled the staff to tailor interventions to the specific needs of these individuals.

> You need to seek out their opinions. You know, really listen to it. And of course, there's a limit as to what we can do, as an organization. We can't do everything. But the fact that they're being asked, that their opinions are being solicited, I think it's very important because more than ever, they're the ones who are afflicted by this disease, right? So, we can't just assume that this is what they need. (Marisol, staff member, semi-structured interview)

G. Supporting persons with dementia to practice social inclusion and care for others

A remarkable feature of the community organization was that not only staff, but also persons with dementia actively practiced social inclusion. For example, when the first author began fieldwork, several persons with dementia welcomed her, asked her about her research, and volunteered to help her. When one learned that she was a relatively new immigrant in Canada and that her family lived abroad, he tried to provide her a sense of belonging saying: "Keep in mind that for now we're your family, you're part of us and we're happy to have you here." Additionally, they practiced social inclusion with their peers through small acts and gestures as illustrated in the following fieldnote excerpt:

> Irina has various mobility issues. Luke, one of her peers, is constantly willing to assist her: he takes Irina's walker and positions it for her, he accompanies Irina in the transitions from one room to the other, and helps her to stand up and sit down ... Luke constantly makes sure that Irina participates in the activities and feels part of the group: "You do as much as you can ... the important thing is that you ... stay here with us." Today, I noticed that Luke was trying to help Irina to stand up, and I had the reflex to take his place and do it myself, fearing that both could fall. But one of the staff members, Michelle, prevented me from doing it: "It's going

to be fine, let him do it, I'm keeping an eye on him." (Participant observation)

As exemplified in this fieldnote excerpt, staff members were willing to take a certain amount of controlled risk to allow persons with dementia to practice social inclusion with each other. Staff members claim that they did not explicitly teach persons with dementia how to practice social inclusion – persons with dementia started this practice on their own. They were possibly inspired by the environment itself and the positive response they received from staff members each time they performed acts of social inclusion. For example, Pamela pointed out that when Sarah welcomed Betsy (a person with dementia who had problems integrating into the group) with a full hug, staff celebrated it with affirmative expressions: "Oh, that's so cute, so lovely!"

Within this environment, certain persons with dementia regain confidence to assume roles of service that they used to play in the past. In the following fieldnote excerpt, Aretha teaches the first author how to "properly" arrange and serve the after-lunch cookies:

> I have just finished rapidly putting the cookies on a plate and I am ready to bring them to the lunch table. Suddenly, I notice that Aretha is looking at me with a disapproving smile: "You don't know what you are doing, let me help you." She folds the napkins as if they were the leaves of a flower and put the cookies on top of them. Then, she symmetrically arranges the different types of cookies according to their shapes and sizes. The platter looks like a garden. I am impressed and ask her how she learned to do this: "I have a lot of experience as a host. I always hosted parties for my extended family." Then, she graciously takes the platter in one of her hands and distributes the cookies among her peers. She comes back to me and tells me she loves to look after others. (Participant observation)

Research has largely portrayed people with dementia as recipients of support, overlooking the recursive acts of care for themselves and others that these persons constantly enact (Ward et al., 2018). Our findings highlight the capacity of people with dementia to play active caring roles and to complement the work of staff members.

Discussion

This study describes the in-action practices of social inclusion that were considered meaningful by both persons with dementia and staff at a community-based organization. There are three novel contributions of this research. First, in-action practices of social inclusion are detailed and described, highlighting the situated and contextual negotiation of enacting broader principles of social inclusion in a community-based setting. Second, while many of our findings reflect principles that have been well-established in person-centered care, they highlight two practices of social inclusion that have received little attention to-date: the constant solicitation of feedback from individuals with dementia; and the practices of social inclusion enacted by individuals with dementia with their peers and with staff. Third, we examine the quotidian actions that constitute effective practices of social inclusion as they are experienced by individuals with dementia. By providing detailed descriptions of these practices, we aim to facilitate their partial translation to other community-based organizations and multiply inclusive environments for persons with dementia.

Community-based organizations for persons with dementia and their caregivers have emerged as a powerful tool for fostering social inclusion (Fortune & McKeown, 2016; Hare, 2016; Williams, 2013). While there is a growing body of literature focused on the best-practices, good practices, and evidence-based practices of social inclusion derived from these organizations (e.g. Askari, Bilbrey, Garcia Ruiz, Humber, & Gallagher-Thompson, 2018; Tanner et al., 2015), there is a little research on how these general recommendations are executed by care providers and experienced by persons with dementia. Most studies do not provide specific examples of how these recommendations are implemented or negotiated in the environments in which they are practiced (Lillekroken, Hauge, & Slettebø, 2017), impeding their translation and uptake in similar community organizations. Our study extends the research lens to capture the various ways in which social inclusion is pragmatically enacted by focusing upon actions, which are imbued by the meaningfulness to and intended purpose of the agent.

Many of our findings are in direct alignment with the Alzheimer's Society's practice recommendations for 1) person-centered care; 2) information, education, and support for individuals living with dementia and their caregivers; 3) staffing; and 4) supportive and therapeutic environments (Fazio et al., 2018). However, our bottom-up approach highlighted practices that were not echoed in these comprehensive recommendation documents, particularly supporting persons with dementia to practice social inclusion with, and to care for, others. This practices not only horizontalize the relations between persons with dementia and staff/caregivers, they allow persons with dementia to benefit from the pleasure, fulfillment, and satisfaction engendered by giving support and care to others. Moreover, the practice of supporting persons with dementia to practice social inclusion and care for others instills an environment where compassion percolates through different relationships and is not only a duty of staff and caregivers. Such in-action practices of social inclusion constitute an example of social citizenship, as they entitle persons with dementia to experience opportunities to grow and participate in their own care and the care of others (Bartlett & O'Connor, 2010). However, the enactment of social citizenship in our study was dependent on certain structural conditions (e.g. low client to staff ratios). In different scenarios, they might only endow people with dementia with what Annette Leibing (2018) has called momentary citizenship, or a form of citizenship that lasts for a limited amount of time at the cost of maintaining structural conditions that are detrimental for long-term dementia care provision. While this stands in contrast to the steady-state social citizenship enabled by the community organization in this study, it may only be possible to negotiate momentary citizenship in the context of other organizations, and should not be discounted due to its transient nature; further study is required to understand the experiences of social inclusion of persons with dementia in these circumstances.

The results of our study have several immediate clinical implications. First, they highlight the effectiveness of community-based organizations in fostering the active connection of persons with dementia with others, providing further evidence for clinicians and family members to promote these groups for persons with mild to moderate dementia. Second, the examples provided in the fieldnote and interviews excerpts demonstrate how the simple practices of being responsive to critique, adaptive to individual personalities and daily circumstances, and actively present for individuals with dementia are experienced as meaningful acts of social inclusion by staff members and individuals with dementia alike. As higher levels of social inclusion have been linked to positive clinical outcomes (Leung et al., 2015), the results promote the integration of these in-action practices into the daily interactions of all those who work with this population. Finally, the results underscore the untapped potential of enabling persons with dementia to include and care for others as a means of fostering active connection, and encourage all working with this population to provide opportunities for persons with dementia to contribute to providing care for their peers, staff, and community.

Clinical implications

- Community-based organizations can be effective at supporting the active connection of individuals with dementia with others, and should be promoted for individuals with mild to moderate dementia.
- Incorporating practices of being responsive to critique, adaptive to individual personalities and daily circumstances, and actively present into daily interactions are experienced by individuals with dementia as effective acts of social inclusion.
- Supporting persons with dementia to practice social inclusion and to care for others instills an environment where care is not just the duty of staff, balances relationships between persons with dementia and staff, and gives persons with dementia the pleasure, fulfillment and satisfaction engendered by giving support and care to others.

The results of our study need to be interpreted within the context of several limitations. First, our research was based on ethnographic methods; social desirability may have caused participants to report what they believed would be pleasing to the researcher. However, we believe that the advantages

of using ethnographic methods in the context of working with persons with dementia far outweigh this limitation. Ethnographic methods provided an effective way of incorporating the point of view of persons with dementia into the understanding of practices of social inclusion due to the integration of the researcher in their everyday activities and the consequent lower impact of his/her presence. In this study, we found that participant observation was a particularly suitable method to capture experiences of persons with dementia, as it does not solely rely on verbal communication, and allows the researcher to focus on the enactment of practices. Additionally, informal interviews enabled us to gather information *in situ* when a person with dementia or staff members were practicing social inclusion, so persons with dementia did not have to rely on their memories (as in the case of semi-structured interviews) to talk about social inclusion. These methods have enormous potential to vividly capture the experiences of persons with dementia (e.g. Brijnath, 2014; Kontos & Naglie, 2006; Leibing, 2017) and should be actively incorporated into future research in this population. Second, practices that were identified as not effective in fostering social inclusion were not included in our study, nor were individuals with advanced dementia, who did not participate in the Aisenstadt Activity Center. Third, as we have reported elsewhere, ethnicity and culture influence how an individual perceives acts of social inclusion, and can be used as an effective tool to include individuals with dementia (Motta-Ochoa et al., 2021). Staff members and individuals with dementia included in this study were multicultural and multilingual, influencing the particular acts that were experienced as inclusive. Finally, the in-action practices we have described may only be applicable to persons with mild and moderate dementia and may not be effective with socially-unresponsive individuals, who do not participate in community-based programs and require institutionalized care.

Conclusion

Through participant observation, informal and semi-structured interviews, we identified seven social inclusion practices experienced as meaningful by both persons with dementia and staff members at a community-based organization: ensuring time for individualized relationships, building schedules centered around flexibility, empowering decision-making, normalizing dementia-related behaviors, involving family members, soliciting and integrating persons with dementia's feedback, and supporting persons with dementia to practice social inclusion. The detailed description of these practices contributes to the growing literature about programs and interventions for persons with dementia implemented by community-based organizations. Additionally, the bottom-up approach used to explore in-action practices of social inclusion illustrates how to enact them in specific contexts, complementing the top-down approach of the abundant recommendations for implementing quality dementia care. This bottom-up approach also revealed practices (e.g. supporting persons with dementia to practice social inclusion and care for others) that have a significant potential for empowering persons with dementia to become active care partners. Finally, our study demonstrates that ethnographic methods are valuable and effective tools for incorporating the perspective of persons with dementia to the understanding of in-action practices of social inclusion. An ethnographic detailed description of these practices can potentially facilitate their dissemination to similar community-based organizations.

Disclosure statement

No potential conflict of interest was reported by the authors.

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