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Sonia Nizzer
VHA Home HealthCare

Stacey Ryan
VHA Home HealthCare

Sandra M. McKay
VHA Home HealthCare

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Cover Page Footnote

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The little things: Exploring perceptions and experiences of client and family-centred care through photovoice

Sonia Nizzer, *VHA Home HealthCare, snizzer@vha.ca*

Stacey Ryan, *VHA Home HealthCare, sryan@vha.ca*

Sandra M. McKay, *VHA Home HealthCare, smckay@vha.ca*

Abstract

Healthcare in Canada is undergoing a paradigm shift, moving away from a prescriptive approach to care delivery to one that prioritizes clients and their families at the center of their care. In the homecare sector, this approach is commonly referred to as client- and family-centred care (CFCC), a philosophy emphasizing the need for point-of-care providers to partner with those receiving care and their families in a way that is respectful and attuned to their individual needs and goals. This philosophy helps homecare agencies like VHA Home HealthCare deliver care to families that embraces what is most important to them. At VHA Home HealthCare, CFCC is well established through education sessions delivered to staff. Despite these efforts, there is limited evidence to confirm whether this education aligns with what is important to clients and families. To address this gap, this study engaged a unique homecare population - parents of children with complex medical needs - to understand how they experience and perceive CFCC using an arts-based approach called photovoice. Through participants' photographs and in-depth interviews, seven core themes were identified which we refer to as *'the little things'* of CFCC. Results of our exploration show that in some cases there is alignment between parents' perceptions of CFCC and the organization's, but there are also many gaps that could be filled by incorporating the unique voices of participants into the organization's educational curriculum.

Keywords

Client-and family-centred care, home care, children with complex medical needs, photovoice, client experience, client engagement

Background

Healthcare is undergoing a paradigm shift, moving away from a traditional prescriptive approach to care delivery to one that prioritizes patients and their families at the centre of their care. In the homecare sector, this approach is commonly referred to as client-and family-centred care (CFCC), a philosophy emphasizing the need for point-of-care providers to partner with those receiving care and their families in a way that is respectful and attuned to their individual needs and goals.¹⁻⁵ In Canada, this concept has been widely endorsed by provincial government institutions; in 2015 Ontario released the Patients First Act followed by a three-year plan for the home and community care sector to further reinforce the notion that healthcare must be, fundamentally, patient-centred.⁶ In the same year, the Registered Nurses Association of Ontario (RNAO) updated their best practice guideline on Person-and Family-Centred Care alongside Accreditation Canada which updated its standards to increase its focus on CFCC, signaling to healthcare organizations that the spotlight on client-and family-centred care would be strong.^{1,3,5} Moreover, mounting evidence from the acute care sector suggests that a client- and family-centred approach could

lead to positive healthcare outcomes such as improved quality of care and improved provider and client relations.^{1-3, 5, 7} Despite the growing body of knowledge supporting the CFCC approach, how it should best be executed remains unclear today. There is also limited evidence to support the homecare sector in understanding the experiences and perceptions of CFCC from the perspective of clients and families. Specifically, a lack of research exists exploring the meaning of CFCC for parents of children with complex medical needs; a unique paediatric population receiving care at home.

Due to advances in healthcare treatment and quality, children who require complex care are moving from hospital environments to their homes to receive ongoing care. Parents are now assuming many high-risk care responsibilities with some support from homecare organizations.^{8,9} Parents of children with complex medical needs are experts in knowing their child's needs¹⁰ and therefore are integral to our understanding of the experience and impact of homecare for this patient population. As central figures of the care team, parents are navigating, advocating, and coordinating all aspects of their child's care in a complicated health system. They

experience high chronic levels of stress due to the intensity of caregiving which can at times be exasperated by system navigation challenges, fragmented services and the multitude of professionals coming into the home.⁸⁻¹⁵ These children receive multiple services from different organizations, each with their own processes and policies, affording parents a unique perspective and voice in the conversation about CFCC.

With pressures to meet clinical goals and deliver quality care in short timeframes, point-of-care providers have expressed difficulties consistently implementing CFCC into their practice^{2,16} and organizations have struggled to find the right strategies to support providers.^{1,17} Despite these challenges, homecare remains an area of the healthcare system with optimal conditions for an intimate examination of CFCC whereby clients can help providers understand the client and family perspective.

Organizational Practice

At VHA Home HealthCare (VHA), an Ontario-based homecare organization, CFCC is promoted as a philosophy that helps the organization deliver care to families while embracing what is most important to them. Although there are no standardized approaches to supporting all point-of-care providers in embedding CFCC into their practice, VHA developed a mandatory education session for providers to learn and reflect on the principles of CFCC (see Table 1). The content of this education is largely informed by three tools: (1) The RNAO 2002 Best

Practice Guideline on Client Centred Care; (2) client complaints and (3) client compliments data. Between 2015 and 2018, the organization delivered the education 75 times to a total of 688 point-of-care providers (inclusive of personal support workers, nurses and rehab professionals). The education is presented from a generalist perspective without population-specific examples. Despite a wealth of evidence-based theoretical content, there is little to suggest that clients were consulted in content development. This lack of client engagement makes it difficult to determine whether the content aligns with clients’ and families’ perspectives on and interpretation of CFCC.

The purpose of this study was to engage parents of children receiving homecare services to develop a deeper understanding of their perceptions of CFCC and what influences their experience, through photovoice. Photovoice: an art-based methodology that encourages communities to share their words and photographs to reach decision-makers and implement positive change.^{18,19} The use of art-based tools in healthcare to understand client experience is increasing; the flexibility inherent in photovoice makes it an ideal approach to elicit authentic expression and depth of the lived experience of CFCC.¹⁸⁻²⁵

The emergent themes were used to examine whether underlying constructs of CFCC education at VHA are in alignment with parents’ perspectives. The targeted study population included any parent whose child was receiving complex care from one or more of VHA’s homecare

Table 1. VHA Home HealthCare’s CFCC Education Principles

Principle	Description
Respect	Addressing client by preferred name, respecting client wishes and concerns. Valuing choices even if these conflict with the point-of-care provider.
Human Dignity	Caring for the whole client, not just a problem or diagnosis. This is seeing the person as a whole – not just a task. Provide privacy, ask permission, avoid elder speak and the use of the term “we.”
Client are Experts for their own lives	Client are experts in their own lives. Whereas providers are experts in clinical practice. This is the idea of partnering with clients and not parenting them.
Client as Leaders	Follow the lead of clients with respect to information giving, decision making, care in general and involvement of others.
Clients’ goals coordinate care of the healthcare team	Ask Clients their goals and make these the priority of their care.
Continuity and Consistency of Care and Caregiver	Be consistent with your word. Make sure other caregivers know what the preferences are – keep them up to date and communicate concerns with the circle of care.
Timeliness	Provide prompt response to client needs. Discuss how you are going to meet concerns. Arriving on time.
Responsiveness and Universal Access	Care that is offered to clients is universally accessible and responsive. The same standard of care is applied to all clients regardless of age, culture, ethnic background, gender, sexual orientation, socio-economic status, etc.

services: personal support, nursing and/or rehab. The organization identifies children with complex care as those whose medical fragility requires them to have continued dependence on their parents and meet one or more of the following conditions: (1) technology dependence, (2) high intensity care (>16hrs/wk.), (3) fragility, (4) chronicity and (5) complexity; adult-aged children (>21yrs) may also fall into this category depending on their fragility.

It is expected that learnings generated from this study will provide an opportunity for organizational leadership to reflect on current CFCC practices and identify where improvements could be made to ensure that greater understanding and support are available to point-of-care providers.

Methods

The study received institutional ethics approval from the University of Toronto.

Sample

Participants were recruited through convenience sampling and identified by case supervisors. Eligible participants needed to identify as parent to a child/ren receiving complex care services through the one of the organization's three lines of clinical services. To capture a broad range of participants, no limitations were placed on medical diagnosis of client: parents of children who have life threatening illnesses, "*congenital or acquired multisystem diseases, severe neurological conditions with functional impairments, clients with cancer or cancer survivors with ongoing disability*"²⁶ (physical or developmental) were all eligible candidates. No age limit was incorporated into our exclusion criteria as there are many examples of children at the organization who chronologically-speaking may appear as adults but developmentally are considered adult-aged children and continue to receive the same level of high intensity care they received as children; this group remains under the children with complex medical needs umbrella at VHA and we see the value of their inclusion into the study.

In keeping with photovoice best practice recommendations, a small sample size was used for this study to ensure the research team was able to develop a trusting and meaningful relationship with each participant throughout the duration of the study.¹⁸ The recruitment target was set at 8-10 families.

Design

A client partner who represented the study population joined the research team and supported the research process on various levels including co-design of the protocol; this individual was not a participant in the study. The inclusion of a parent helped the research team to create an equitable and collaborative process while being sensitive of the power differences that can often appear

between researchers and participants.²⁷ The theoretical foundation of this study is grounded in visual ethnography operationalized as photovoice, underpinned by the theory of social constructivism. Social constructivism creates learning environments where individuals are free to draw and present meaning that provides researchers an authentic perspective.^{27, 28} Literature strongly recommends that researchers begin to move beyond conventional frameworks to engage clients and families when trying to examine client perceptions and experiences. Traditional methods of data collection like surveys are limited in their ability to elicit client or family member's true thoughts and perspectives.^{25,29,30} Photovoice lends itself well to this type of inquiry as it emphasizes a community's voice as central to findings. The visual data produced by participants captures emotions or issues that may be difficult to fully understand solely through verbal or written communication. Participants actively participate in data creation and assigning meaning to each photograph which helps the research team connect the dots and understand the broader implications.^{19,20}

All participants received an honorarium in the form of a gift card for their participation.

Changes to Methodology

Modifications to the original method were made to exclude weekly group facilitation; the unpredictability of parent's lives related to their child's fragile health state would have prevented them from being able to make such a commitment to the study. Baker & Wang²⁰ discussed making similar changes to the methodology when working with frail, health populations, and similarly the limitation in doing so; preventing participants from engaging with their peers in fulsome discussion that could have contributed to a deeper understanding of their experiences and perceptions. Having a parent on the research team helped ensure that all components of the methodology were sensitive to the time commitment of this fragile population.

Data Collection and Materials

Data was collected in the four phases of photovoice outlined in Table 2. Each participant received a 20-megapixel digital camera, a microSD card, and a training kit prior to data collection. Demographic data was collected in Phase 1; participant's gender, care recipient's age, length of time receiving services from the organization, and type of services utilized were collected to build a participant profile. The research team was available to support device troubleshooting throughout Phases 1 and 2.

Table 2. Four Phases of Photovoice

Photovoice Phase	Phase Description
Phase 1: Photography and Ethical Training	<p>Participants were invited to attend a group meeting with the research team to receive and review study materials. At this meeting the research team provided:</p> <ul style="list-style-type: none"> • A review of the purpose of the study and the informed consent forms • Demographic information on care recipient collected • Training on how to take pictures using the digital camera • A review of ethical considerations around taking photographs in the community using a guide to ethical photovoice research²⁹ • A participant brochure, that included an overview of the study goals, and guiding questions to help anchor their point-of-view throughout study. <p>Participants were granted permission to use their own digital cameras, however, a microSD memory card with a corresponding ID was still issued to ensure that the content generated for the study remained private. Individuals who could not attend the meeting were provided a one-on-one meeting at their home by a member of the research team.</p>
Phase 2: Photography Assignment	<p>Participants were given three to four weeks to take photographs. No limitation was set on the number of pictures participants could take. Members of the research team were in-touch with participants at the two-week mark to check in, provide any troubleshooting support and schedule interviews.</p>
Phase 3: Interviews	<p>In-depth, audiotaped interviews were conducted to examine photographs in more detail. The interviews were one-on-one with the participant and a member of the research team. The interviews were semi-structured and guided using the PHOTO caption worksheet. Participants created captions for up to five pictures that most accurately represented their perception and experience of CFCC; these pictures would be exhibited and used for knowledge translation purposes. Participants were finally invited to attend and present their work at the community exhibit at the end of the study.</p>
Phase 4: Community Exhibit	<p>At the end of the study an exhibit was held to present participant’s photographs to community members and organizational leaders at VHA Home HealthCare. Participants had an opportunity to interact with attendees and reflect on their work.</p>

Data Analysis

Data analysis was guided by the DEPICT method³¹ of qualitative analysis and supported by two research students who did not have any insider preconceptions about the study population. Analysis was completed over five stages with frequent group meetings. The first stage involved dynamic reading of the transcripts by each member, isolating concepts or patterns. The second stage involved a group meeting to present and discuss concepts and patterns and collaboratively identify relationships to create themes; a preliminary codebook was developed to organize categories and sub-categories with descriptors to be used in the coding process. Next, careful line-by-line coding of interview transcripts was completed using the codebook; where necessary, updates were made to the codebook after group discussion. Images were clearly referenced in transcripts and were tagged with a suitable code. The fourth stage of analysis included inclusive reviewing and summarizing of themes; the coded data in each category was re-reviewed, taking note of key quotes and images to compile a summary for each category for a final analytical review. At the final review stage group members deliberated and reflected on the content,

revisiting the objectives. A discussion was held until consensus was reached to finalize emerging themes.

Descriptive analyses were applied to summarize and describe the data collected regarding participant demographics and CFCC education activity within the organization.

Findings

Participants

Seven parents; six female primary caregivers (85.7%) and one male primary caregiver completed all phases of the photovoice protocol. The mean age of children being cared for by participants was 16.6 years (range: 11 mos-33 years); one participant cared for a complex adult-aged child (>21yrs). On average, a parent and child had been receiving VHA services for 5.5 years (median length of service: 8 months, range: 3 mos-14 years). Most participants cared for one child with complex needs; one parent had two children receiving complex care from VHA. Participant and child characteristics are presented in Table 3.

Table 3. Participant and Child Characteristics

Characteristic	Frequency (%) n=7 parents
<i>Gender of Parent</i>	
Female	6 (85.7)
Male	1 (14.2)
<i>Age of Child Receiving Care</i>	
0-6 years	2 (25.0)
7-16	2 (25.0)
17-33	4 (50.0)
<i>Length of Services Received by Organization</i>	
0-1 years	4 (50.0)
10+ years	4 (50.0)
<i>Type of Service Utilized</i>	
Personal Support Worker (PSW)	8 (100)
Nursing	3 (37.5)
Rehab Provider (Occupational Therapist)	4 (50.0)

Over 100 photographs were generated throughout the course of the study. Each family contributed five to seven pictures that most represented their understanding and experience of CFCC; 50 photographs were submitted altogether. Ultimately, photographs and interviews helped the research team understand what matters most to this

Figure 1. That Little Touch: Photograph of a PSW and client holding hands symbolizes the bond between provider and child



caregiver population through seven core themes (see Table 4). We refer to these themes as *'the little things'* of client- and family-centred care, to emphasize the layer of nuance that is brought to our understanding of viewpoints shared by participants.

Theme 1: Provider Qualities and Relationship

The qualities and relationships created between families and point-of-care providers accounted for the greatest number of photographs taken by participants. Parents described their experiences with phenomenal providers

who were able to forge special bonds with their children when describing CFCC. Being a skilled and competent point-of-care provider was described as very important to parents, but equally as important to them was the ability to create meaningful relationships with the family. To achieve this, participants added that it takes trust, patience and love.

"There's a real connection that takes place, she treats her like her sister. You don't realize it, but when you have had so many people coming through your home, it's very stressful, but these are the little things you remember." [ID76]

Great point-of-care providers are regarded like members of the family and parents saw this as a special achievement in care. Despite the challenges of the job, parents felt that when providers showed love and care in the home it always left a lasting impression. As seen in Figure 1, the photographs that were taken by participants around this theme reflected a tenderness and bond between providers and their clients; an integral component of CFCC.

Theme 2: Beyond the Care Plan

Parents described many instances in which their point-of-care provider was flexible and went beyond their job description to use some of their care visit to do something beyond the list of clinical tasks they were required to complete. Going beyond the care plan was depicted as an activity that gave new experiences to clients; something that could be fun to break-up the monotony of their sometimes-sedentary lives or taking initiative to complete a household task that needed immediate attention. Parents used words like "flexible," "initiative" and "creativity" to describe those experiences they had when their providers went above and beyond the care plan during a visit. By being flexible in their duties, providers shifted from task-oriented to client-centred. Figure 2 represents this concept of being flexible and showing initiative during a care visit to include a fun activity.

Figure 2. Wherever they need to go, and they go. This photograph of a bus represents going beyond the care plan



Table 4. Overview of emergent themes and corresponding images and text

Themes and Sub-Themes	# of Images	Examples from interview transcripts
Provider Qualities and Relationships	15	<p>“There’s a real connection that takes place, she [the PSW] treats [my daughter] like a sister.”</p> <p>“Doing a craft. This is an example of a PSW coming in and doing other activities that are important to Jim. They are both happy. I want them [PSWs] to feel good about coming here and working with him. “It’s like when you are in school. If the teacher is good and trying to help you out, you are happier to go every day. But if [the teacher] is just not good, she’s not helping you, you don’t feel good to go to school.” “It’s like she [PSW] is a teacher, friend and a worker.”</p> <p>It’s relief for me because I find that I’m always rushing in the mornings. I’m like that crazy mother in the morning because I need to get him outside by a certain time to get the bus, and I got to prepare his lunch. So, with this picture, I took it because I didn’t need to do that. And I found that I was always rushing whenever I’m giving him his breakfast...but with her here, I find that she’s able to take her time. And he can be a bit difficult during feedings. But for her, she’s very patient, I find, so I appreciate her patience.”</p> <p>“You don’t realize it, but when you have had so many people coming through your home, it’s very stressful, and there’s little things I remember, like one time I asked somebody to make scrambled eggs for my daughter...and I could tell that the heart wasn’t in it when she was making them. I feel that like with food and care; everything has to have love in it. And if it doesn’t, I don’t want it. It doesn’t work for me, because I want the best for my daughter. And I want people that love her and that are able to have that. So little things like that I remember just noticing. It’s really just doing things with you heart.”</p> <p>“This is the first-time having spaghetti. And she was having a blast. The occupational therapist might have been there to help me through her eating. She’s been such a help. She’s [available] by phone, by emails...and I know that she has kids of her own. So, she gives me tips. And not just on the occupational therapy side, but just in general. So, we’ve built a relationship.”</p>
Beyond the Care Plan	7	<p>“We talked about J having something to do and so she helps him with writing his name. That is not her job, right? But the bathing and changing, it takes 30-45 minutes and there’s an hour she’s here.”</p> <p>“I’m always the one holding his hand to take him outside to the school bus. And I just found it interesting how she just took the initiative to do it instead of relying on me...for once, I didn’t have to do this.”</p> <p>“The city is not always easy to get around in a wheelchair, but part of planning for J, is figuring out what stations are wheelchair accessible. So, we’ve got to research, it’s an added step that you take into account. But really the nurses who are responsible for him try to plan out the steps, they take that on, which I think is great.”</p> <p>“We had a nurse once who came to me and said this side bag on his wheelchair was ripping. She had a needle and thread to sew it. Now that would not be in any nurse’s job description, but she saw it needed to be done and again, that’s the right thing to do.”</p>
Consistency	4	<p>“Consistency is important for [my daughter] and for us because we are planning the whole day. If somebody new comes in, we can’t make plans, it’s hard for us. Now I have to explain everything again.”</p> <p>“She needs two people for the bath. To take her in to the bathtub. It actually hurts me to see her taking a bath. Oh, it’s very difficult because I can’t just have anybody giving her a bath...she’s all bones...and you cannot put her in a chair with her back touching it without a lot of padding there. So, if there’s no padding there, she’ll come out of there like she did one day, all red and scratched up, and it’s horrible. It’s painful and it’s horrible, if it’s not done right, it’s very upsetting.”</p>

Table 4. Overview of emergent themes and corresponding images and text (continued)

Themes and Sub-Themes	# of Images	Examples from interview transcripts
Communication a. Between providers and families/client b. Between family and the organization c. Between providers	5	<p>“I always want to know, ‘Did she eat much? What did she eat? How much? So those are communication things. It’s all communication between the caregiver and us that should happen.”</p> <p>“If my PSW is not going to make it because of an emergency I get a phone call from the office and they time they call you isn’t the greatest because they call you at 3:25pm to say they they’re not going to be here for 4pm. Well that’s not good for us.”</p> <p>“The OT and PSW have met once. The OT was kind of telling her [the PSW] how to look for cues when she's done, how to feed her, never to force-feed her, and really some exercises that I've been doing with her as well. And I think that that was a great thing to do. It just kind of happened by fluke. They just overlapped. For clients that also have an OT, any other services with VHA, it would be beneficial for everyone to get together. So. everyone's on the same page and kind of work together on their client.</p>
Respect Our Home	4	<p>“People sometimes don’t remember that this is his home and his room and it’s really important to make sure that it stays neat. And that garbage is not left around.”</p> <p>“Patches [the dog]; she is a part of our family.”</p> <p>“That’s his bed. On that particular day the nurse actually did make his bed and kept his room nice and neat and clean. And I think that’s really important. Especially for the next person coming in. In many cases, the nurses don’t clean up after themselves, so it’s just kind of left there and it accumulates. So that’s really important.”</p>
Dignity	7	<p>“It’s all about remembering that there is a person at the other end of service.”</p> <p>“This is putting away dishes; part of his routine. Sometimes she [the PSW] will help him if there’s a lot and she’ll just put a few things away and help him. But, usually he does it on his own. So that makes him feel- I like him to feel useful in the house, so it’s not just the caregiver, it’s also he’s participating.”</p> <p>“She is trying to help J to put properly his food towards his plate independently. She is teaching him to be more independent. For me if he can eat by himself, bite finger food, it’s excellent...she is encouraging him to do things independently as he is getting older.”</p> <p>“Obviously their [nurse’s] skills are important and their comfort level with managing his fragility and his unpredictability. But also, remembering first and foremost, he's a person and you have to interact with him as a person.”</p>
“Put Yourself in Our Shoes” Empathetic Intelligence	4	<p>“...put their self in our shoes. I guess people don’t understand this if it’s not related to their family. Unless they’ve experienced this, they don’t know what you really have to go through or how chaotic it is.”</p> <p>“It shows the scar in more depth. The grooves, and where the lines were, in case her heart failed. But this one, I look at it, and she's come such a long, long, long way. And it's just emotional to see this because of what she's all been through.”</p> <p>“I think people need to see that they’re working with very fragile people. The fragility of her situation and being sensitive to that is important. They [staff] have to be very sensitive. And they need to understand how to be sensitive in the home.”</p>
Additional Learnings about what care means to families	4	<p>“She comes during a critical time and it’s a relief, it makes those days go so smoothly. I don’t feel that pressure on my shoulders.</p> <p>“She wouldn’t be the way she is if [the organization] wasn’t around to help.”</p> <p>“You [parents] have to be more open towards workers coming in, embracing them, whoever they are, of any culture whatsoever. And the workers should be embracing the client.”</p>

Theme 3: Consistency

When offering insight into their daily lives, parents detailed the specificity and complexity of their children's medical care. They emphasized the need for consistency and routine, particularly when it came to their point-of-care providers. Providers who had been with their families for several years knew the particulars of the children's care needs and their routine. This put parents at ease and allowed them to continue their precisely scheduled days without worrying that something would be missed.

"When [her regular PSW] is here, I know it's going to be done right because she knows what to do. When she was on vacation, the other two didn't have the experience and I needed to be there just to make sure that it was being done right." [ID71]

When frequent changes to schedules and providers occurred, it disrupted the entire household. Parents reported having to cancel other obligations to dedicate time to explaining pertinent details around care all over again, often having to monitor the care to ensure proper procedures were followed. Figure 3 captures an example of a highly sensitive task that required a specific protocol, only performed well when the family's permanent providers are there for the visit. When those providers are not available, this causes a great deal of stress on the household.

"Consistency is important for her and for us because we are planning the whole day. If somebody new comes in, we can't make plans, it's hard for us. Now I have to explain everything. You're basically doing it all again because you have to show them what's the routine. It's the whole teaching process all over again and if my other daughter has practice after school, forget about it." [ID73]

Figure 3. Bath Day. This photograph of PSWs giving a bath represents how lack of consistency can cause a great deal of stress during very high-risk tasks



Theme 4: Communication

For many parents, good communication was vital. Three facets of good communication were outlined by parents (1) parent and provider communication (2) parent and organization communication and (3) provider to provider (interprofessional) communication. Many parents spoke positively about the communication between their current point-of-care providers and themselves, explaining that open and honest dialogue between them was essential to care (see Fig. 4).

Parents also spoke honestly about their frustrations with poor communication, particularly when providers could not make a shift and the families are notified at the "last minute" by the organization's customer service teams. They expressed that they are working tirelessly to balance competing demands and are bound to strict schedules; transparent communication and timely notice gave them enough time to plan and make adjustments. As explained by one family, late notification was often devastating and could throw their entire days into disarray and/or put their child at risk.

"I get a phone call on my cell [from the office] and the time when they call you is not the greatest because they call you at 3:25pm to say that they're not going to be here for 4pm. Well, that's not good for us. Because we could be at work or something like that and nobody would be home, we need that information earlier." [ID73]

Lastly, communication exchange between the entire care team, including different professionals, was highlighted as a noteworthy facet of CFCC. A few parents received more than one service from VHA and described how impactful open communication and exchange of information

Figure 4. Getting a report. This photograph of a parent, provider and child represents the importance of communication between provider and parent



between interprofessional providers was on the care of

their child; this in turn strengthened the parent's confidence in the organization.

"The OT and PSW have met once. The OT was telling the PSW how to look for cues, how to feed her...and I think that's a great thing to do. For clients that also have other services, it would be beneficial for everyone to get together. So, everyone's on the same page and works together." [ID80]

Theme 5: Respect Our Home

Parents expressed that having care at home could be challenging at times because of the clinical transformation that takes place. Parents felt that providers could be insensitive to this and dismiss the comfort, security and values that they worked hard to maintain for the entire household. They felt that when point-of-care providers enter a client's home they needed to consider how to balance respect towards the environment while also providing quality care. One way to achieve this was expressed through the idea of cleanliness and waste management. Because many of the children received care in different areas of the home, keeping things tidy was important. Some parents described that seeing their home free of care-related clutter gave them and their child a sense of order and a semblance of normalcy in their sometimes-chaotic environment (see Fig. 5).

"People sometimes don't remember that this is his home and his room and it's really important to make sure that it stays neat. And that garbage is not left around and that nurses or PSW's clean up after themselves... [my son] doesn't make a mess, but the people around him might and it's important to just clean up after." [ID71]

Respecting the home also meant respecting the entire household, including pets. Pets were considered members of the family and parents emphasized the importance of

Figure 5. His Bed. This photograph of a child's bed neatly made represents the importance of respecting home environment where care is provided



providers being aware of this prior to coming to their homes (see Fig. 6). If providers reacted unfavourably towards pets in the home, it adversely affected the relationship with the family and could lead a family to ask for a different provider.

"You can't be afraid of Remy, he's a part of the family and requires just as much attention and care as everyone else." [ID78]

Figure 6. Remy the dog.



Theme 6: Human Dignity

Parents spoke passionately about honoring the dignity and abilities of their children as an integral part of their understanding of CFCC. They expressed the importance of everyone seeing their child/ren as individuals not defined by their limitations. Figure 7, a picture of the sky, represents a participant's wish for her son to be viewed as a person with opportunities and possibilities.

"He's not simply a tube to be fed or a body to put medication into...it's all about remembering that there is a person at the other end of service." [ID79]

Figure 7. Sky's the limit. This photograph of the sky represents the idea of client dignity



By offering these client's choices in their lives, speaking with and not down to, and including them in care not only created opportunities for autonomy and independence but also allowed for positive social interactions that build their confidence for the future.

"There was a nurse who took [my son] into a health and beauty store, and they just went through smelling the different shampoos. He is non-verbal but his nurse asked him, 'Do you like that smell? Do you like this smell? and they'll go and help him choose a scent." [ID79]

Theme 7: Put Yourself in Our Shoes

Participants reflected on their lives caring for their children and spoke to the acute stress they experienced supporting their child through different crises, hospitalizations and illnesses. Parents who had been caregiving for over 10 years and those who were relatively new and adjusting to the changes shared similar experiences. Other reflections from participants included what it was like caring with minimal or no assistance and the difficulties of relating to other parents. Parents expressed that opportunities for relief were infrequent and the impact of stress could manifest in many ways affecting them physically and emotionally.

Parents took photographs like Figure 8 to emphasize the importance of providers understanding the fragility of every situation they walked into and recognizing that there is often much more going on at home than meets the eye. To them, CFCC also meant taking the time to understand the family situation and having emotional intelligence. A parent explained that one 'little thing' providers could do to be more empathetic in the home was to not take the occasional negative interaction between them personally, explaining that sometimes, she could be having a bad day that contributed to her negative mood.

Figure 8. Her back. This photograph of a client's back showing bones protruding is meant to represent the the emotional and physical fragility in the home



"I was so overwhelmed with her medication and her recovery from open-heart surgery. I was wary of people just coming over." [ID80]

"I think people need to see that they're working with very fragile people. The fragility of her situation and being sensitive to that is important. And [providers] need to understand how to be sensitive in the home. They also have to understand that I've been dealing with this for 10 years, and this is the hardest thing ever. You can't even image as a mother what I've had to go through and what it means to see my daughter like this." [ID78]

Additional learnings were uncovered through the one-on-one interviews that were important representations of what receiving care meant to parents. A few photographs opened up dialogue that helped researchers understand that families are very appreciative of the care they receive and that there is a large dependence on services in order to cope with their present situations. These additional insights into homecare help ground our understanding of client experience and are an excellent reminder of the vital work that is done by homecare providers.

The themes that emerged through photovoice were compared with the core principles of CFCC education at VHA Home HealthCare to determine if what is taught in the classroom to point-of-care providers is aligned with the perspectives and experiences of paediatric clients and families. We see alignment occur across four areas: (1) Respect (2) Human dignity (3) Timeliness as it refers to communication and (4) Consistency (see Table 5). The areas in which alignment is unclear, are indicators of where VHA can focus improvement efforts.

Finally, we were able to achieve our desire for community engagement through hosting several community exhibits for organization leaders and community members. The exhibits allowed for key decision makers to reflect and engage with clients in a new and meaningful way. Several participants were able to attend the exhibit and expressed their gratitude for the opportunity. Afterwards, a parent who participated in the study suggested that we create a digital and hardcopy photobook to disseminate findings and improve education efforts.

Discussion

By the weaving of participant's photographs and one-on-one discussion, we have come to describe the experiences and perceptions of client- and family-centred care through the expression 'the little things.' 'The little things' is a colloquial phrase that was used by a parent to explain what mattered most to her during care of her child; the small, non-clinical, practical gestures by point-of-care providers that reflected a truer essence of CFCC. Through examples shared by participants, we see 'the little things' reflected in all of the identified themes: (1) Provider Qualities and Relationships (2) Going Beyond the Care Plan (3)

Table 5. Comparison of VHA CFCC education principles and themes emerged from photovoice

VHA Client-and Family-Centred Care Teaching Principles	Photovoice Themes						
	Provider Qualities and Relationship	Beyond the Care Plan	Consistency	Communication	Respect Our Home	Dignity	Put Yourself in Our Shoes
Respect					●		
Human Dignity						●	
Clients are Experts for their own Lives							
Clients as Leaders							
Clients' goals coordinate care of the healthcare team							
Continuity and Consistency of Care and Caregiver			●				
Timeliness				●			
Responsiveness and Universal Access							

Consistency (4) Communication (5) Respect for the Home (6) Dignity and (7) “Put Yourself in Our Shoes” (emotional intelligence). Simply put, parents want point-of-care providers who are kind, consistent and care about the impact they make on their client’s life; are willing to be flexible with their time to ensure that their young clients have a rich and purposeful life while being sensitive to the challenges and stressors family’s experience. Clients and families are “*not asking for the moon*,”⁵² when it comes to receiving client-centred care; their expectations are reasonable and achievable.

We find some commonalities between our homecare-specific results with other Ontario-based healthcare institutions that have published documents related of CFCC. The RNAO in its most recent best practice guideline established a set of CFCC themes-developed by an expert panel of professionals, clients and families. We see congruence in themes around the need to build therapeutic relationships between providers and families, knowing the whole person, emphasizing that a person is not defined by their health condition and finally effective communication and consistency.⁵ Similar themes are reflected in works released by other homecare organizations, that build on these concepts and include the importance of provider empathy as a component of CFCC.³ Some of the perspectives from our study are also reflected in studies that focus on the experiences of senior caregivers in homecare. In a study by Fraser et al.,²³ they discovered that provider qualities and relationships played

a large role on the overall homecare experience for clients and caregivers.

The differences between parents’ perspectives and the current CFCC education principles could be explained by the absence of consultation with clients and families at the time of content development. An apparent gap our findings demonstrate is around timely communication between clients and the organization’s customer service centre— emphasizing that CFCC does not stop at the point-of-care and all organizational employees can benefit from CFCC education. These knowledge gaps can be bridged between organizations and clients by creating opportunities to co-design education content for providers. Clients and families bring valuable perspectives to the education of health professionals, specifically being able to contribute to the teaching principles around soft skills and real-life application of clinical skills.³³

Since ambiguity around what CFCC means and how it is operationalized remains today,^{1, 2} these findings could help point-of-care providers contextualize CFCC in a way that helps them see what is meaningful to families. Photography is an arts-based knowledge transfer tool that leaves impressions on our psyche- it taps into an emotional facet that cannot be easily forgotten. These tools can easily be incorporated into teaching environments while being sensitive to different learning styles. For organizations to deliver on their commitment to CFCC, it is vital for point-of-care providers to fully embrace this philosophy.² The inclusion of participants’

photographs and quotes offers a more nuanced snapshot into the lived experience of families of children with complex medical needs and reflects real-life examples to offer a deeper and more impactful learning experience to help providers be more adept in the home.

Limitations

While we found much success in executing photovoice with parents of children with complex medical needs, the study had several limitations that must be acknowledged. The study engaged a small percentage of the children with complex medical needs population at VHA Home HealthCare. It would be difficult to suggest that these results are representative of the entire paediatric population due to the study's small sample size. We suggest that future projects consider increasing the sample size so that it is more representative of the homecare population and consider recruiting participants from more than one organization. Furthermore, as this research was conducted with a homecare focus, the findings may not necessarily be generalizable to other healthcare contexts.

Conclusion

Understanding CFCC from the perspectives of clients and families help motivate organizations to align their policies, education and support for staff to be more reflective of what client's value. Through photovoice, participants provided a unique perspective of what it means to be client- and family-centred through *the little things*. Our findings support our conclusions that clients and families have attainable expectations of receiving CFCC and want providers to be thoughtful and more attuned in the home, paying special attention to the interactions and relationships created with the entire family. The visual data created by parents can help to facilitate the knowledge translation and bridge the gap in learning. We have seen an increase in the use of arts-based tools in transformative learning environments due to their effectiveness for education and practice change. Photographs have a cerebral way of causing us to be emotionally attached to the subject of the photograph; helping us connect to feelings, memories and experiences. We believe that incorporating parents' voices and imagery into the organization's existing CFCC curriculum can help point-of-care providers connect to the content in a profound way that could ultimately enhance their practice and the client experience.

Moving forward, we see opportunities for homecare organizations to co-design education with clients and families to develop content that reflects client and family experiences.

References

1. Bender D, Holyoke P. Bringing Person-and Family-Centred Care Alive in Home, Community and Long-Term Care Organizations. *Healthcare Quarterly*. 2016;19(1):70-75.
2. Kuo DZ, Houtrow AJ, Arango P, Kuhlthau KA, Simmons JM, Neff JM. Family-Centered Care: Current Applications and Future Directions in Pediatric Healthcare. *Maternal Child Health Journal*. 2012; 16:297-305. doi:10.1007/s10995-011-0751-7
3. Bender D. *A Guide for Implementing Person and Family-Centred Care Education across Healthcare Organizations*. Saint Elizabeth Healthcare; 2016.
4. Saha S, Beach MC, Cooper LA. Patient Centeredness, Cultural Competence and Healthcare Quality. *Journal of National Med Assoc*. 2008;100(11):1275-1285.
5. Registered Nurses' Association of Ontario. *Person-and Family-Centred Care Clinical Best Practice Guidelines*. Toronto, ON: Registered Nurses' Association of Ontario; 2015:1-60.
6. Ontario Ministry of Health and Long-Term Care. *The Patients First Act Background*. Toronto, ON: Queen's Printer; 2016.
7. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW. The Impact of Patient-Centred Care on Outcomes. *Journal of Family Practice*. 2000;49(9):796.
8. Woodgate RL, Edwards M, Ripat J. How families of children with complex care needs participate in everyday life. *Social Science & Medicine*. 2012;75:1912-1920.
9. Elias, ER, Murphy, NA, Council of Children with Disabilities. Homecare of Children and Youth with Complex Healthcare Needs and Technology Dependencies. *Pediatrics*. 2012;129:996-100. doi:10.1542/peds.2012-0606
10. Resch JA, Mireles G, Benz MR, Grenwelle C, Peterson R, Zhang D. Giving Parents a Voice: Qualitative Study of the Challenges Experienced by Parents of Children with Disabilities. *Rehabilitation Psychology*. 2010;55(2):139-150. doi:10.1037/a0019473
11. Kirk S, Glendinning C. Supporting "expert" parents - professional support and families caring for a child with complex healthcare needs in the community. *International Journal of Nursing Studies*. 2001;39:625-635.
12. Woodgate RL, Edwards M, Ripat J, Borton B, Rempel G. Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics*. 2015;15(197):1-15. doi:10.1186/s12887-015-0514-5
13. Dewan T, Cohen E. Children with medical complexity in Canada. *Paediatric Child Health*. 2013;18(10):518-522.
14. Kirk S, Glendinning C, Callery P. Parent of nurse? The experience of being the parent of a technology-

- dependent child. *Issues and Innovations in Nursing Practice*. 2004;51(5):456-464.
15. Whiting M. What it means to be the parent of a child with a disability or complex health need. *Nursing children and young people*. 2013;26(5):26-29.
 16. Coyne I, O'Neill C, Murphy M, Costello T, O'Shea R. What does family-centred care mean to nurses and how do they think it could be enhanced in practice. *Journal of Advanced Nursing*. 2011;67(12):2561-2573. doi: 10.1111/ j.1365-2648.2011. 05768.x
 17. McMillan SS, Kendall E, Sav A, et al. Patient-Centered Approaches to Healthcare: A Systematic Review of Randomized Controlled Trials. *Medical Care Research and Review*. 2013;70(6):567-596. doi:10.1177/1077558713496318
 18. Palibroda B, Krieg B, Murdock L, Havelock J. *A Practical Guide to Photovoice: Sharing Pictures, Telling Stories, and Changing Communities*. Winnipeg, Canada: Prairie Women's Health Centre of Excellence; 2009.
 19. Wang C, Burris M. Photovoice: concept, methodology, and use for participatory needs assessment. *Health Education Behavior*. 1997;24:369-387.
 20. Baker T, Wang C. Photovoice: use of a participatory action research method to explore the chronic pain experience in older adults. *Qualitative Health Research*. 2006;16(10):1405-1413. doi:10.1177/1049732306294118
 21. Wiersma EC. Using Photovoice with people with early-stage Alzheimer's disease: A discussion of methodology. *Dementia*. 2011;10(2):203-216. doi:10.1177/14713012111398990
 22. Aubeeluck A, Buchanan H. Capturing the Huntington's disease spousal carer experience: A preliminary investigation using the "Photovoice" method. *Dementia*. 2006;5(1):95-116. doi:10.1177/1471301206059757
 23. Fraser K, Archibald M, Nissen C. Uncovering the Meaning of Homecare Using an Arts-Based and Qualitative Approach. *Canadian Journal on Aging*. 2014;33(3):246-258.
 24. Janes N, Cowie B, Bell K, Deratnay P, Fourie C. Revealing and acting on patient care experiences: exploring the use of Photovoice in practice development work through case study methodology. *International Practice Development Journal*. 2015;5(11):1-12.
 25. Balbale SN, Morris MA, LaVela SL. Using Photovoice to Explore Patient Perceptions of Patient-Centered Care in the Veterans Affairs Healthcare System. *Patient Experience Journal*. 2014;7:187-195. doi:10.1007/s40271-014-0044-5
 26. Cohen, E, Kuo DZ, Agrawal, R., Berry, JG, Bhagat, SKM, Simon, TD, Srivastava, R. Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*. 2011;127 (3): 529-538. Doi: 10.1542/peds.2010-0910
 27. Creswell J. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 2nd ed. London: Sage; 2007.
 28. Andrews T. What is social constructionism? *The Grounded Theory Review*. 2012;11(1):39-46.
 29. LaVela SL, Gallen AS. Evaluation and measurement of patient experience. *Patient Experience Journal*. 2014;1(1):28-36.
 30. Evans-Agnew RA, Roseberg M-AS. Questioning Photovoice Research: Whose Voice? *Qualitative Health Research*. 2016;26(8):1019-1030. doi:10.1177/1049732315624223
 31. Flicker S, Nixon, SA. The DEPICT model for participatory qualitative health promotion research analysis piloted in Canada, Zambia and South Africa. *Health Promotion International*. 2014; 30(3):616-624. doi:10.1093/heapro/dat093
 32. Fooks C, Obarski G, Hale L, Hylmar S. The Patient Experience in Ontario 2020: What Is Possible? *Healthcare Papers*. 14(4):8-18.
 33. Towle A, Godolphin W, Katz A, et al. Active patient involvement in the education of health professionals. *Medical Education*. 2010;44:64-74. doi:10.1111/j.1365-2923.2009. 03530.x