

# The Little Things: Exploring perceptions and experiences of client and family-centred care through PhotoVoice

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## BACKGROUND

Client and Family-Centred Care (CFCC) is a philosophy that helps VHA Home HealthCare (VHA) deliver home care to families that embraces what is most important to them. At VHA, this philosophy is well established through internal education developed with the support of best practice guidelines and delivered to point-of-care providers.

Despite these efforts, there is limited evidence to confer that this education reflects what is most important to clients and families in this unique care setting and no evidence that clients and families were engaged in content development of the internal education.

## OBJECTIVE

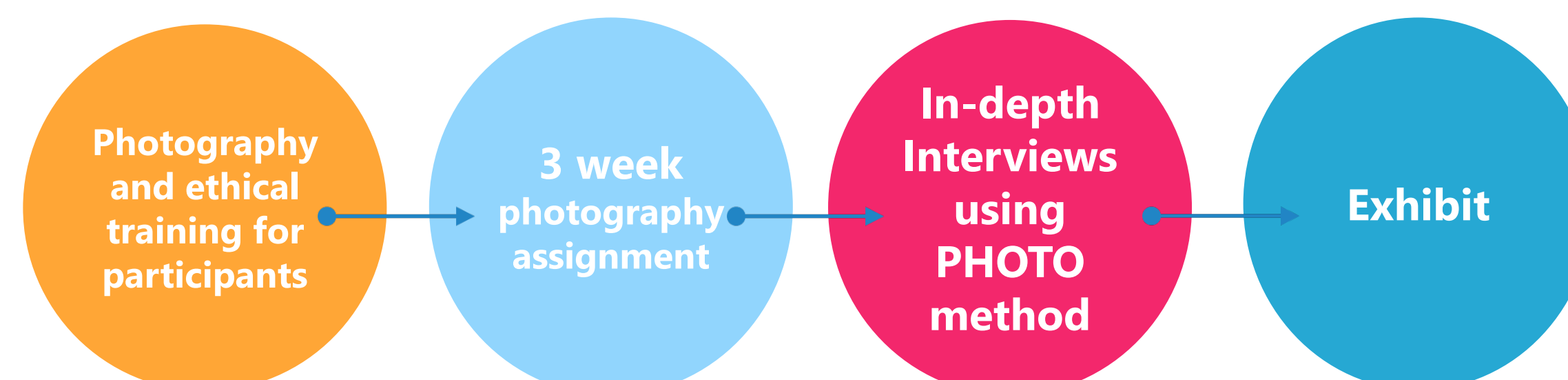
To engage parents of children with complex medical needs receiving services from VHA, as co-researchers to explore their **perceptions** and **experiences** of CFCC through the approach of **Photovoice**.

Using traditional methods of data collection, like surveys are limited in how much a client or family member can express their true thoughts and perspectives. Literature strongly recommends that researchers begin to move beyond conventional frameworks to engage clients and families when trying to examine patient perceptions and experiences<sup>1</sup>.

The emergent themes generated from photograph and interview data, will be used to examine if underlying constructs of CFCC education is in alignment with parent's perspectives and practice improvements can be made within the organization.

## METHODS

Data collection was conducted using the qualitative approach of visual ethnography operationalized through PhotoVoice. Participants were asked to participate in the 4 phases of PhotoVoice:



In Phase 2, participants were provided with digital cameras and asked to take pictures of elements in their environment, to visually interpret their perceptions of CFCC and their experience of CFCC during a homecare visit. Phase 3 involved in-depth semi-structured interviews examining the photographs taken by participants in detail, focusing on narrative and open ended questions using a tool called the PHOTO method caption sheet. Thematic analysis of interviews was undertaken. Themes were then compared to the values and beliefs underpinning CFCC education to determine if there is alignment.

## RESULTS

Seven families (n=7) participated in the study and generated a total of 37 photographs. Analysis of discussion revealed that what is important to families are the **little things** that point-of-care providers do during home care services that make a lasting positive impact. It is through the little things that parents experience or perceive Client and Family-Centred Care.

The **‘little things;’** a term coined by a participant, are characterized by small, non-clinical, proactive gestures by point-of-care providers that go beyond their typical job descriptions to provide comfort to clients and their families; these small actions are significantly valued and influence how client and families come to understand CFCC. These gestures can include, taking the initiative to repair a small rip in fabric of a favorite toy, holding a client's hand, greeting a client at arrival and departure and/or simply acknowledging that a parent has had a difficult day and making them a cup of tea.

Figure 1 presents the themes and sub-themes drawn from the thematic analysis.

Themes relating to dignity and independence are echoed in current CFCC education however there is not enough contextualization to bring meaning and understanding to these ideas.

Figure 1: Themes and sub-themes



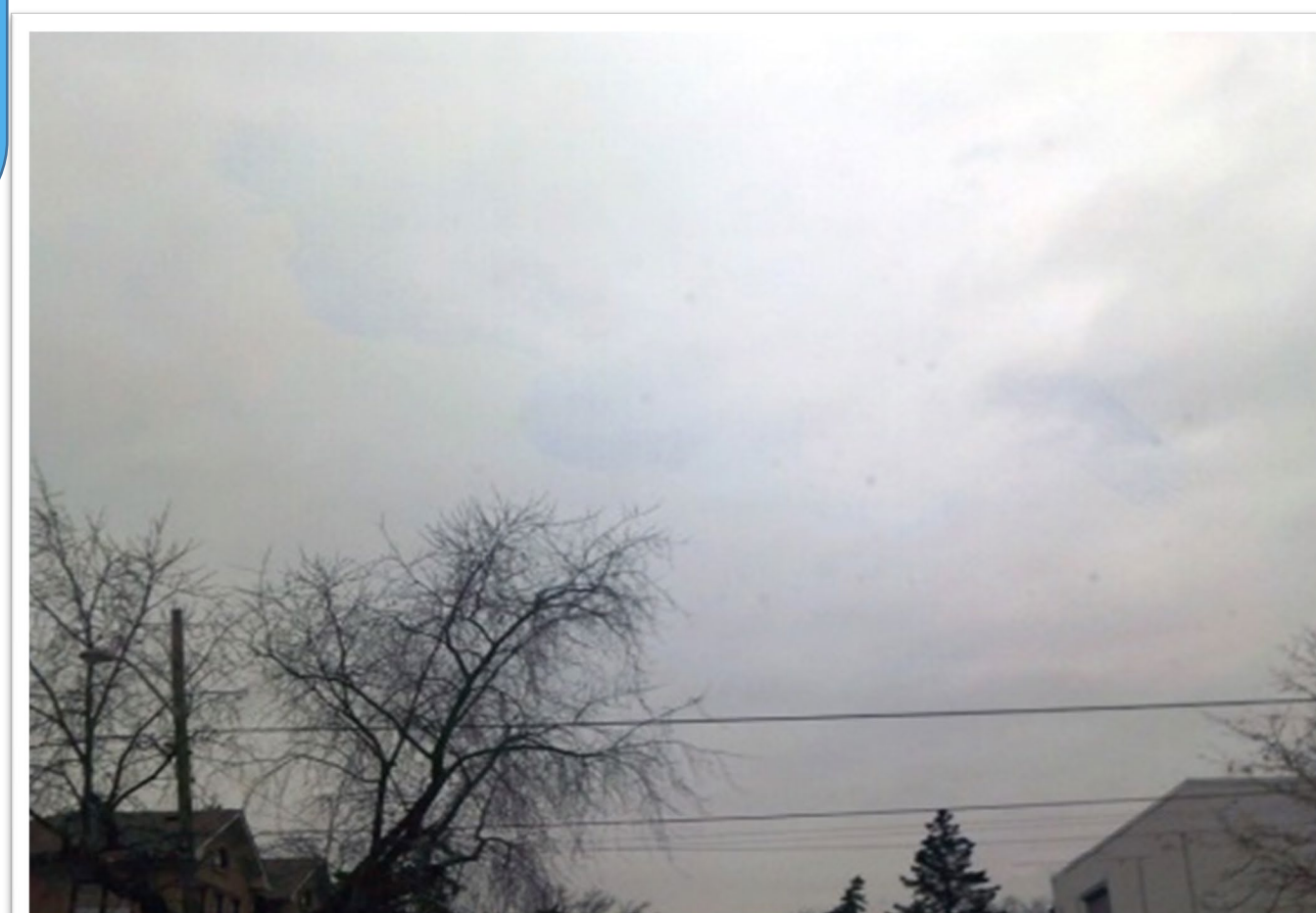
"If somebody just holds her hands or just massages her little fingers rather than just sitting there doing nothing, that's what I look for, little things like that." F.D



"She always asks, we still have time what can I do to help you. After all the regular duties are done, they're either having a nice conversation, helping with writing or doing a craft...she's like a teacher, a friend and also a PSW and I like that" E.B



"He's a person first and foremost; and you have to interact with him as a person. He's not simply a tube to be fed or a body to put meds into...he's a person that needs to be interacted with and not at." M.W



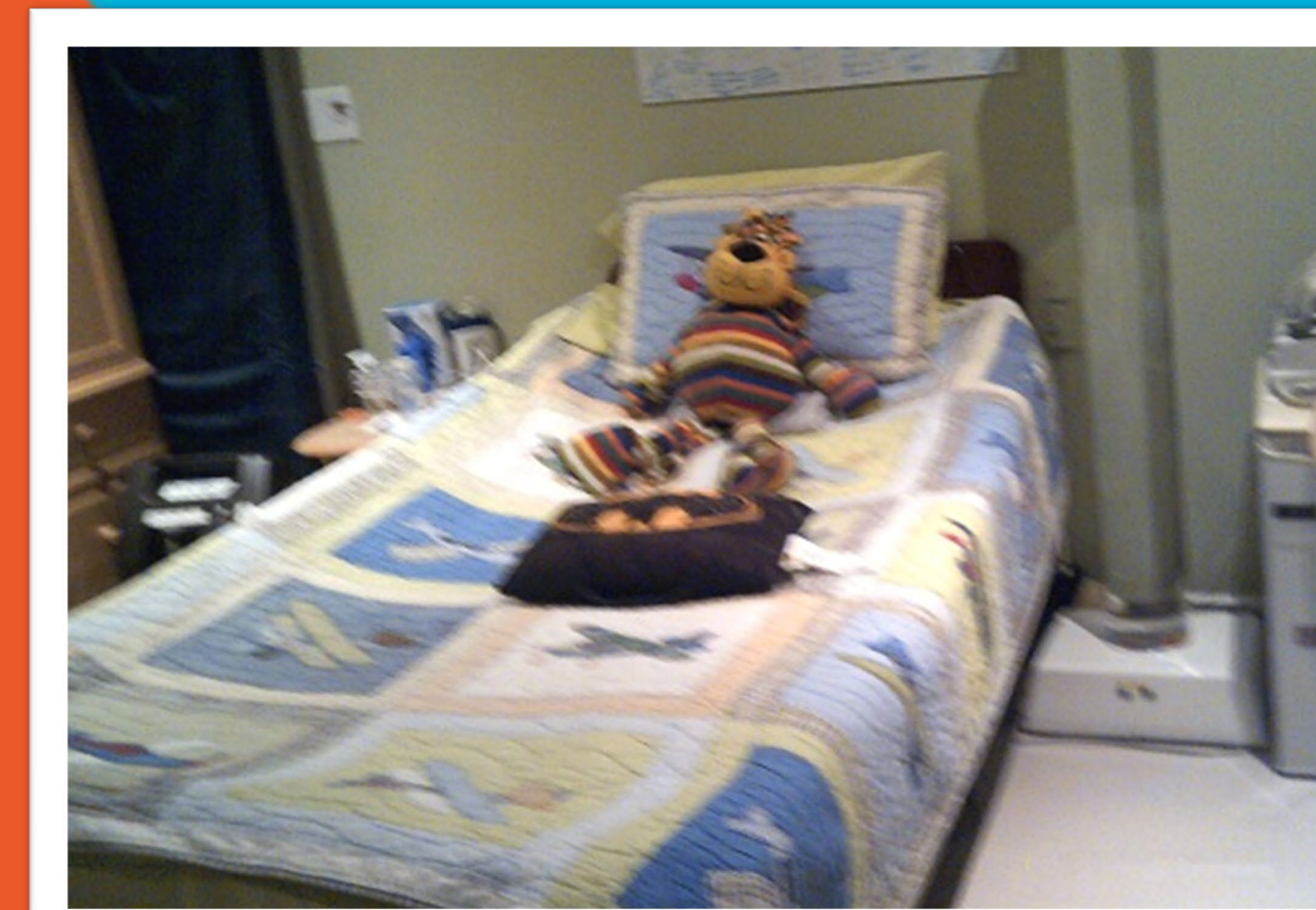
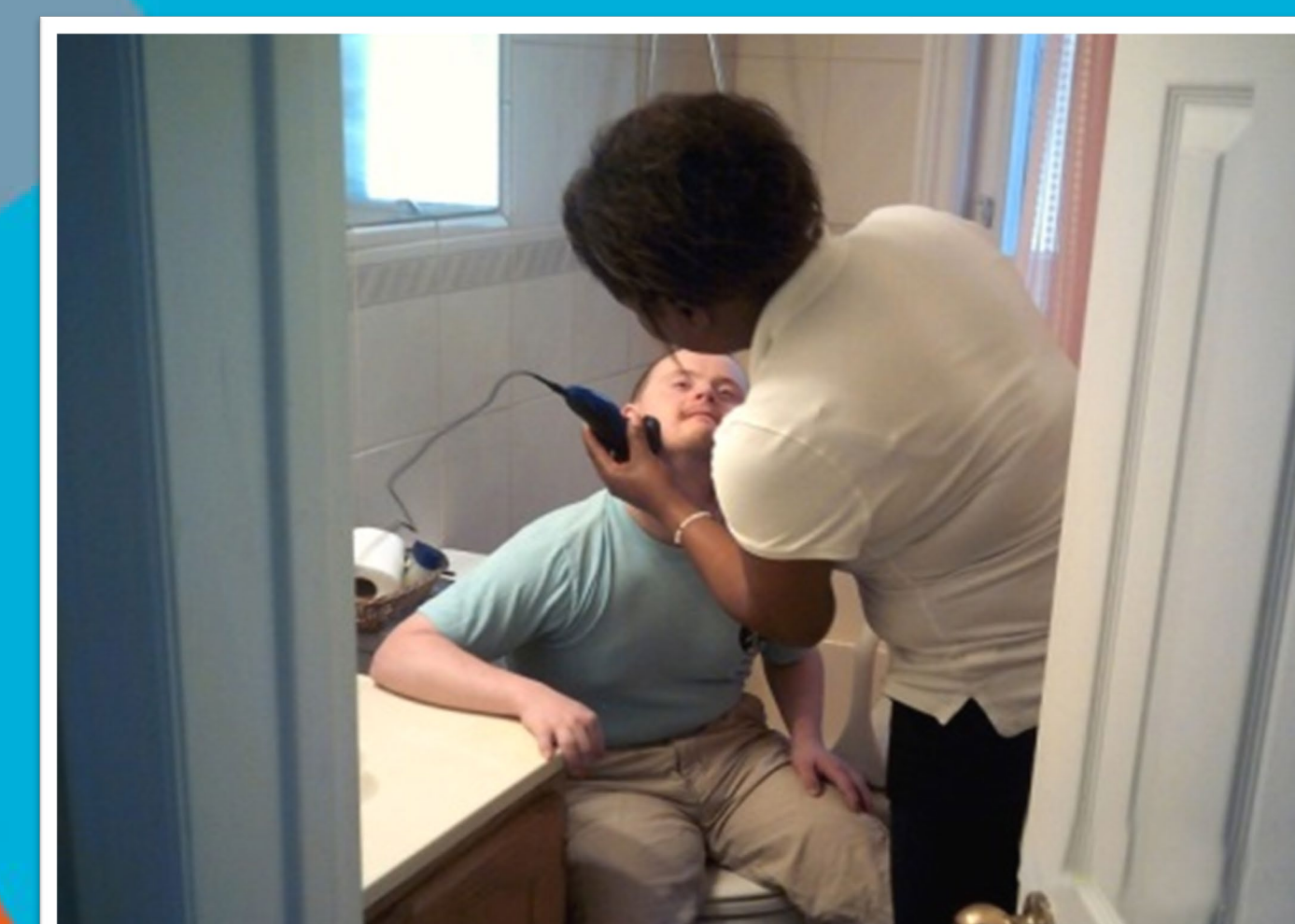
"The idea is for him to have the richest, most full life possible and it's not at home it's out in the community. He likes to be out doing and seeing. Sky's the limit" M.W

## CONCLUSIONS

The flexibility inherent in using PhotoVoice methodology made it an ideal approach to elicit authentic expression of lived experience<sup>2</sup>. Despite some alignment between parent's perspectives and education constructs, there are many experiences and perceptions that go beyond what is taught in the classroom. We believe that improvements can be made by the following recommendations:

(1) the visual stories generated from this study be incorporated into the present CFCC curriculum to offer a more nuanced understanding of what families believe to be Client and Family-Centred Care; the little things.

(2) the process of education development at VHA move toward a **co-design model** where clients and families work collaboratively with the organization to develop content that prioritizes the client's voice and experience.



## REFERENCES

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- 2Wang, C.C., & Burris, M.A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behaviour*, 24, 369-387.

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