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# Capturing the experiences of FASD prevention workers through quilting

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### Article abstract

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## Capturing the experiences of FASD prevention workers through quilting

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### Abstract

*Visual data collection methods are gaining momentum in the field of qualitative research because of their ability to document the social world and experiences of participants (Banks, 2001; Rose, 2001). This study employed quilting as a data collection method to capture the experiences of 47 Fetal Alcohol Spectrum Disorder (FASD) prevention workers in the Parent Child Assistance Program (PCAP) across Alberta. Specifically, this article focuses on the process of creating the quilt, the impact that this data collection method has had on participants and researchers, as well as a discussion of our next steps and suggestions for future opportunities to use quilting methods in community-based research.*

### Introduction

Qualitative methods have long been considered a means of understanding and exploring the meaning that individuals and groups ascribe to aspects of their lives (Creswell, 2009). This meaning is most typically sought through words; collected through interviews or focus groups. However, qualitative approaches also encompass a range of visual data collection methods, such as photography and quilting, which have been gaining momentum because of their usefulness in documenting and representing the social world and improving understanding of participant experiences (Banks, 2001; Rose, 2001). In many ways, visual media allows us to access the perspectives of participants more directly, as we can “*see someone else’s point of view and borrow their experience for a moment*” (Weber, 2008, p. 45).

In particular, quilting has been recognized as an innovative visual technique that allows the researcher to integrate participants’ stories into a meaningful collective experience (Koelsch, 2008), as was one of the goals in working with our participants, members of the Parent Child Assistance Program (PCAP).

Although quilting is relatively new in its use as a data collection method, previous studies have found that quilting is associated with cognitive, emotional, and social wellbeing, and is experienced as therapeutic by participants (Dickie, 2010; Burt & Atkinson, 2011). Quilting has also been used as a medium to help participants tell their stories related to significant life events (e.g. transitioning out of homelessness; Washington, Moxley, & Garriott, 2009). The following article will outline the process of creating the quilt, explore how this experience has impacted both the participants and the researchers, and discuss how this study might inform future community-based research projects involving front-line workers in other FASD prevention and support programs.

## The program

PCAP is an evidence-based home visitation program for women with a history of alcohol and drug abuse who are at risk of giving birth to a child with a fetal alcohol spectrum disorder (FASD). Originally developed by Therese Grant and colleagues in Seattle, WA, PCAP follows an advocacy and case management model in which PCAP mentors help their clients access needed services, complete addictions treatment, and make informed family-planning decisions (Grant et al., 2005). The goals of the PCAP program include assisting at-risk mothers in seeking addictions treatment, ensuring that children are in a safe environment, and linking families with community resources; all with the ultimate goal of preventing future alcohol-affected births.

PCAP is recognized as a promising program for the prevention of FASD and is currently being implemented in both urban and rural settings across Alberta, (Rasmussen et al., 2012) with seven of these PCAP sites operating on the First Nations' reserves of Enoch, Blood, Ermineskin, Saddle Lake, Tsuu T'ina, O'Cheise, and Samson. The fundamental components of PCAP are largely consistent with First Nations' culture in that they emphasize the importance of family and community, they involve strength-based approaches that focus on hope and often involve the use of humor, and they tend to take a holistic approach to client care, with a focus on mind, body, and spirit.

## The purpose

This quilting project was undertaken as part of a larger examination of FASD service delivery in Alberta. Specifically, the purpose of this project was to explore PCAP prevention workers' experiences working on the front lines of FASD prevention efforts in the province. These experiences were collected through a variety of methods (e.g. focus groups), and were further enhanced through the creation of a quilt serving as a visual depiction of participants' collective experiences in the often challenging work that they do. The PCAP program, given its strong evidence base, is subject to frequent research studies and reviews often involving survey methods, the results of which PCAP mentors have reported are of little relevance to their work. Quilting was therefore chosen as a data collection method for this population in part to engage participants and provide them with an outlet for sharing their stories and feeling heard while engaging in a collaborative process, something that was not being accomplished through previous research.

## The process

Forty-seven PCAP prevention workers (45 women and 2 men) from sites across Alberta participated in

this quilting project. Included in this group were PCAP service providers, network coordinators, program managers, administrative personnel, and leadership team members, with representation from all 10 FASD Service Networks across the province. We are therefore confident that this sample was representative of the larger population of PCAP prevention workers and that participants brought a variety of experiences with differing client populations to this study.

Participants were given an eight inch quilting square and a selection of markers, glitter glue, pencil crayons, and pastels. They were asked to use these materials to share their experiences in working in PCAP using illustrations and/or words. Although a sample square was provided to demonstrate the logistics of creating a quilting square, participants were purposefully given limited directions for this task in order to encourage their creativity. On the back of squares, participants included their name, role, & explanation of their piece. Photographs were taken to document this process, and participants' comments throughout the creation of their quilting square were noted. Overall, participants found the process of creating the squares to be a positive and healing experience; as one participant reported *"[This] was a great way to start the morning...very therapeutic"*. Another participant noted that *"Hope [was] the major source"* of inspiration in creating her piece.



Once completed, the individual squares were collected and given to a master quilter and fellow psychologist, who carefully and thoughtfully pieced these individual works of art together into a quilt. This was a lengthy and intensive process, a labour of love, which involved an interpretation of the content of the quilting squares and the development of an overall theme, layout, and name for the quilt. The quilter documented her experiences creating the quilt and provided commentary on her process and reactions in an interview conducted by a member of the research team.



## The product

The final product is a quilt called *Pick-Up Sticks*, pictured below. The quilter chose this name to reflect the challenging nature of a PCAP mentor's work, which involves supporting at-risk mothers in often difficult circumstances to prevent FASD. *Pick-Up Sticks*, a child's game, is a metaphor for this process in that PCAP mentors must patiently and lovingly tease out the interventions and services that will be the most successful for each individual client. As in the game, each client is unique and will require a different combination and sequence of sticks (i.e. interventions and strategies) to be successful. As the quilter expressed, "[*Pick-Up Sticks*] requires absolute concentration...it requires patience and gentleness and quietness and order to sort out the sticks... That is what needs to be given to people who struggle with FASD...and that's what the people who work with them have...unconditional positive regard....That is what we need to give is unconditional positive regard and patience, love, and support." In addition to the name, each aspect in the design of this quilt has been thoroughly considered. For example, the long scroll shape was chosen to reflect wisdom and higher learning, the green border represents health and growth, while the empty square represents the untold story of those living with FASD.



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conveyed. For example, squares included images of rainbows, flowers, and growth, as well as inspirational phrases such as “love can build a bridge”, “when one door closes another one opens”, and “together we can”. Positive emotional words such as courage, love, hope, beauty, togetherness, happiness, dignity, trust, opportunity, and possibility also abound. As the quilter expressed, *“I was a bit...surprised by how optimistic the quilt was. I expected there to be a lot more of...the cold, hard reality of it and I think that bespeaks the qualities that are necessary in the people who do this work...”*

## The impact

With the quilt recently completed and being disseminated and shared with PCAP prevention workers and other FASD service providers, we are just beginning to see how the creation of this work of art has impacted those involved; both the PCAP members as our participants and the members of our own research team.

**Participant Impact.** Upon seeing a photo of the finished quilt, one participant reported being amazed at how all the “little pieces” came together to make something so complex and beautiful, and she felt that it really reflected the nature of the work she does in PCAP, where all the pieces need to come together “just so”. As we continue to disseminate the quilt and related photos to PCAP sites, it is hoped that participants will be able to see the quilt as a representation of their collective experiences as front line workers, and as a tangible product of their hard work and dedication. This stands in contrast to the nature of the work that PCAP mentors are involved in on a daily basis, in which success and tangible outcomes can often be difficult to see and progress difficult to measure. As one participant explained, *“It’s hard to measure all the births that we’ve prevented... How do you measure babies that weren’t born?”*

**Researcher Impact.** During this process, several of our PCAP participants expressed interest in learning about how the telling of their experiences affected our team of researchers. The team, composed primarily of masters and doctoral-level students, took time to reflect on our experiences of being involved in such an impactful project. Overall, this process was eye-opening and inspiring, opening our minds to new ways of understanding the work that is done with at-risk populations, and helping us to develop an appreciation for the passion and dedication of PCAP mentors. As one student explained about the entire process:

“I know people are quick to judge mothers and look down upon them for putting themselves and their children at risk by drinking, but hearing the stories these front-line workers [told] was a real eye-opener. In our research we are usually focused on the child, their deficits, and [the] interventions they need. This focus on prevention and the struggles that are involved in working with this population... added to my understanding.”

Another researcher commented on the quilt in particular:

“[I was] surprised by the flood of emotions that I was experiencing [upon seeing the quilt]... I felt overwhelmed by the powerful messages of hope and struggle depicted in the squares. I was also moved by [the] level of care, commitment and enthusiasm... expressed in... the quilt. I felt like I was taking part in something very special; which I have never really felt in my past research experiences.”

We are thankful to have taken part in such a reciprocal process, in which we have had the opportunity to give something back to our participants while also taking and learning a great deal from their experiences.



## The future

The use of quilting methods to capture the experiences of PCAP prevention workers across Alberta has been, by our account, an overwhelming success. The quilt itself has added richness to the data collected by other means (e.g. focus groups), and has produced an understanding of the PCAP program and the passion of its mentors that cannot easily be expressed in words. A formal qualitative analysis of the content of the quilt is currently underway, in which common themes will be explored. Given previous research using quilting methods, we anticipate that this analysis will lead to further understanding of participants' experiences and relationships (Banks, 2001; Rose, 2001).

Furthermore, the production of this quilt has allowed us as researchers to give something back to our participants as a means of thanking them for their participation and validating their experiences as PCAP mentors working on the front lines of FASD prevention in Alberta. We believe this to be important in this line of work, in which there is much uncertainty about future outcomes and where success is often difficult to measure. Future research projects might consider the use of quilting and other visual data collection methods when working with other community-based groups and organizations, as they add an element of a personal connection to a traditionally impersonal research process. Particularly with FASD service providers, this innovative technique is a very collaborative and relationship-focused approach which appears to align well with the culture and the philosophy of many FASD prevention and support programs.

Finally, this study provides an important starting point for considerations related to data collection methods that have the strong potential to engage participants to a greater extent than more traditional research methods (i.e., surveys). The high engagement of participants observed during the quilting activity indicates that an emphasis on visual storytelling supported the sharing of experiences that may not have otherwise been accessible. Implications for researchers may be far reaching across all study populations but especially relevant for those collaborating with First Nations, Metis and Inuit peoples.

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