Photo-Elicited Interviews: A Method to Create Open Communication for Mothers Raising Children With Foetal Alcohol Spectrum Disorder

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Abstract
Photo-elicited interviewing (PEI) can make a valuable contribution to understand the lived realities of mothers raising children with foetal alcohol spectrum disorder (FASD), when used as a methodological tool. This article offers an explanation to some of the challenges experienced by these mothers who are often marginalised by a perception of causing wilful harm. PEI was used in a Master’s thesis that described the ways in which mothers promoted the occupational engagement of their children with FASD in the Pixley Ka Seme District in Northern Cape Province, South Africa. The study served as an example of how PEI shifted the power balance between the researcher and the mothers to create a space that encouraged mothers as participants to talk openly and freely about the challenges in their daily lives. PEI promoted the agency of participants and enabled the researcher to learn from them as experts in raising their children. The images discussed during PEI opened valuable doorways to conversation, helping participants prioritise what they want to share, while images acted as reminders during the conversation. Photographs added a visual layer to the verbal data gained through semi-structured interviews, offering a deeper level of insight into the contributions mothers make towards the development of children with FASD.

Keywords
methods in qualitative enquiry, photo elicitation, community-based research, interpretive description, social justice

Introduction
This article will describe the first author’s experience of using photo-elicited interviews (PEI) as a method of data collection during a Master’s research study entitled: Mother’s facilitation of the occupational engagement of their children with foetal alcohol spectrum disorder (FASD). This study aimed to describe the ways in which mothers promote the engagement of their children with FASD in occupations of productivity (work and school), leisure (play) and self-care. Furthermore, it aimed to describe the personal, environmental and occupational factors that the mothers expressed as limiting and the factors they described as enabling in their attempts to facilitate occupational engagement.

The article starts with a brief description of FASD and offers an overview of alcohol use from an historical perspective. This is followed with a description of the context in which the study was conducted and a rationale for why PEI were selected as a main method of data collection. The findings that emerged from the research are presented with an emphasis on the role of PEI as well as the experience of the researcher and participants, concluding with the way in which PEI helped to raise the voice of a marginalised group.

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Foetal Alcohol Spectrum Disorder

Prenatal alcohol exposure is a leading cause of developmental disability (Kalberg et al., 2006; Nash, 2012), with a lifelong debilitating impact. The teratogenic effect of alcohol was not common knowledge before the French scientist Lemoine described the birth defects in children prenatally exposed to alcohol in 1968 (Calhoun & Warren, 2007; Olivier, 2017). Five years later, American scientists Smith and Jones coined the term foetal alcohol syndrome (FAS) in their Lancet-published article on the syndromic effect of prenatal alcohol exposure (Jones & Smith, 1973).

Not all alcohol-exposed pregnancies result in the full syndrome with growth retardation, neuro-behavioural signs and facial features (Urban, 2017). Various factors including maternal health and nutrition, genetic and environmental factors, timing, amount and pattern of drinking determine the developmental outcome of prenatal alcohol exposure (Kalberg & Buckley, 2007; Olson et al., 2009). This phenomenon gave rise to the umbrella term foetal alcohol spectrum disorder (FASD) in their Lancet-published article on the syndromic effect of prenatal alcohol exposure (Jones & Smith, 1973).

Children with FASD live with cognitive, emotional, developmental, behavioural, sensory and physical challenges (Abele-Webster et al., 2012; Culshaw, 2015; Mattson et al., 2011; Murthy et al., 2009; Nash, 2012). These challenges negatively impact their adaptive functioning and engagement in their daily occupations (Culshaw, 2015; Whaley et al., 2001) (Figure 1).

A Historical Overview of Alcohol Use

Historically, artisans brewed alcohol on a small scale when excess fruit or grain was available from as early as 7000–6600 BC (Urban, 2017). Ancient tribes consumed alcohol periodically, and communally, usually to celebrate festivals (WHO, 2014a). Increased access to alcohol during industrialisation (WHO, 2014a) led to social and other forms of harm, including crime, social unrest and poor health (Urban, 2017; Olivier, 2017).

Harmful drinking became distinct from low-risk drinking (WHO, 2014a) because low levels of alcohol consumption may have health benefits, while excessive consumption is associated with alcohol-related harm.

Women are more vulnerable to alcohol-related harm when consuming similar amounts of alcohol in similar drinking patterns than men. Female vulnerability is related to smaller body weight, liver capacity and higher proportion of body fat (WHO, 2014a). In addition, alcohol consumption during pregnancy may cause FASD. Internationally, the drinking pattern amongst women varies considerably (Urban, 2017; WHO, 2014a). Many women in South Africa abstain from alcohol, but those who do drink consume double the amount of alcohol compared to women in Belgium and the USA, as illustrated with data in Table 1 (adapted from Urban, 2017; WHO, 2014b). Amongst pregnant women, this pattern of binge drinking is most dangerous to the unborn baby (Urban et al., 2016).

Cloete (2005; 2012; 2015) described alcohol consumption as an occupation amongst women of childbearing age in the Western Cape. Drinking amongst women seems equally normalised in the Northern Cape where some of the highest prevalence rates of FASD are reported with 12.2% in De Aar (Urban et al., 2008) and 28% in the Renosterberg Local Municipality (Olivier, 2017), both in the Pixley Ka Seme District (red area in the map).

Setting the Scene

The Northern Cape (red and white area in the map, Figure 1) is a large (372,889 km²), but sparsely populated (3.1 people/km²) province (Statistics SA, 2011) with low annual rainfall and extreme temperatures. Pixley Ka Seme District (red in the map, Figure 1), one of five in the province, has unemployment rates as high as 80%, with 70% of the inhabitants living below the poverty line and 20% of the population illiterate (Stassen, 2012). Government grants, including childcare, old age pension and disability grants are the main source of income. The Child Gauge (Delany et al., 2016) reports that child hunger is common in the Northern Cape; in fact, only in Kwazulu-Natal is child hunger more common than in the Northern Cape where, as stated before, FASD is common.

Rationale for Selecting Photo-Elicited Interviews (PEI)

Mothers make a valuable contribution towards the development of their children, but mothers of children with FASD are
often stigmatised (Corrigan et al., 2017; Roozen, 2019) when perceived as causing wilful harm. The first author worked with mothers of children with FASD since 1995. Some of these mothers faithfully brought their children to various occupational therapy interventions although they continued to battle with alcohol use. These mothers took much of what they learnt regarding early childhood stimulation to heart and took pride in their children’s development. They taught the first author the value of mothers as primary agents of change, anchoring her focus on them (Elliot, 2015). In 2017, she embarked on a qualitative descriptive study to understand the ways in which mothers facilitate the occupational engagement of their children with FASD in spite of challenges described earlier.

The naturalistic researcher (Lincoln, 1988) views reality as multi-layered and socially constructed by a culmination of the wide-ranging experiences of an individual. This view allowed the researcher to explore the everyday reality of mothers and generate knowledge ‘grounded in human experience’ (Sandelowski, 2004, p. 1368) as they facilitate the occupational engagement of their children with FASD. The process required her to reflect on the constructions of participants and her own understanding of the contextual meaning to participants as a wall to bounce off their beliefs in order to gain a deeper level of understanding. Paramount to her research was the desire to learn from mothers, acknowledging their expertise through the use of photo-elicited interviews (PEI). PEI as a data collection method promoted the voice of a marginalised group to reveal their collective wisdom.

Collecting data through an interview allows the researcher to gain understanding of people’s experiences and the meaning they make of these experiences (Dunbar & Roberts, 2006). The researcher was guided by semi-structured interviews which allowed for prompts to productively enquire (Galvaan, 2010) and explore her own assumptions. For example, when mothers described their children as busy, the researcher asked a mother to explain what she perceived as busy; it was revealed to include distractible, over-active, tireless and playful.

Participants of this study were selected from a population known to the researcher through pre-existing therapeutic relationships. She had to carefully navigate her position as ‘expert’ while encouraging agency of participants. Photo-elicitation was a participatory way of collecting data (Mitchell et al., 2005) promoting agency of the participants (Graue & Walsh, 1998 cited in Galvaan, 2010) and allowed for prior therapeutic contributions from the researcher to fade away, while participants engaged as experts in their own right during the interviews.

Pierce (2005) emphasised the benefit of visual images to study a topic as complex as occupation. Such visual research places participants in their own context and generates a deepened engagement with their social world (Halford & Kowles, 2005). Visual images, such as photographs, allow insight into the personal-social and space dimensions, adding powerful images to the time dimension exposed in participants’ stories during verbal interviews (Clandinin, 2006). Thus, visual images allow for a fuller description of physical and emotional experiences, when compared to exclusively verbal interviews (Mitchell, 2008). Messages communicated by visual images influence both the viewer and those captured by the image. In this way, visual images offer marginalised groups a voice to advocate for appropriate policies or services (Galvaan, 2010).

Photo-elicited conversation encouraged participants to take the lead in enquiries, share their views, perspectives and experiences, and make full use of their expertise in raising children with FASD (Mitchell, 2008). PEI allowed the researcher and participants to explore the photographs together, ensuring participants’ autonomy to decide what is worth remembering and discussing (Galvaan, 2010). Reading the photographs involves the participant in the analysis and interpretation by critically reflecting on the intent and meaning of messages. In this way, the visual image became a door to engage with participants on a deeper level while discussing their children with FASD. In addition, as a participatory data-gathering method, PEI respects the diversity and complexity of the way mothers facilitate occupational engagement while at the same time, attempting to understand how they raise children with FASD (McCloy et al., 2016).

**How PEIs Were Used to Elicit the Stories of the Mothers**

Approval for the research was granted by the Foundation for Alcohol Related Research (FARR), the University of Cape Town, Department of Health and Rehabilitation Science, and the Health and Science Ethics Committee gave ethical approval (HREC REF. 275/2018). Participants gave written consent via community workers acting as gate keepers (Creswell & Poth, 2018). Gate keepers were familiar with the study population and the process of gaining informed consent. Most participants were familiar with the researcher even if

| Table 1. Selected Drinking Data Amongst Women from Three Countries. | South Africa | USA | Belgium |
|---|---|---|---|
| Lifetime abstainers (15 years and older) | 55% | 17% | 9% |
| Current drinkers (during past 12 months) | 26% | 63% | 80% |
| Alcohol per capita – drinkers only (litres pure alcohol/year) | 16.0 L | 7.8 L | 7.8 L |
they had no direct contact with her. This prior familiarity added to participants’ ability to give or decline informed consent. Even if consent was granted, they had the option not to attend appointments. Gate keepers asserted that mothers’ choice to participate or not would in no way affect future benefits (e.g. participation in support groups) they may gain from the organisation.

Gate keepers recruited nine participants incrementally, and all of them voluntarily met with the researcher. The study was considered to be low-risk as no new diagnoses were made, and care was taken to maintain confidentiality so as to protect mothers from stigmatisation. The researcher worked in the community, serving a variety of clients; thus, participants could not be identified as mothers of children with disability or with FASD. Furthermore, supportive structures were created for participants who needed it, including referral to the Department of Social Development to formalise one foster placement and the Department of Health for counselling and psychiatric services to adjust medication of another participant.

The primary data collection method was two semi-structured, separate interviews (45–60 minutes duration). During the first interview, the researcher revisited the purpose of the study. The same information was given to all participants, reiterating that they had the right to withdraw at any time without affecting any of the other services offered by the organisation. The researcher presented herself to the participants as a student. She explained her desire to learn from participants whom she considered to have expert knowledge in raising their children with FASD. This helped shift the balance in the research–subject dynamic which usually places the researcher in a position of power in relation to the participant (Elliot, 2015). Before embarking on this enquiry, the researcher had observed mothers using the digital cameras on cell-phones to capture memorable moments when participating in programmes. This observation opened the possibility of using photo-elicitation.

At the end of the first semi-structured interview, the researcher explained in detail how photographs would be used in the following interview. Participants were offered the use of a borrowed cell-phone camera to take new photographs or to bring photographs they already had. All of them preferred to use the cameras on their own cell-phones (McCloy et al., 2016). However, after this arrangement some of the participants asked the gate keeper who had recruited them to assist in taking photographs. This gate keeper discussed the process with the researcher and was encouraged to follow the lead of the mothers, taking only pictures requested by the mothers.

Audio recordings were transcribed verbatim and confirmed within 3 days of recording. Transcriptions for each interview were 5–10 A4 pages, typed in Arial font, size 11. Data were confirmed by listening to audio recordings while reading through the transcriptions. Raw data were reviewed using thematic analysis to identify and report themes based on what emerged from the data (Creswell & Poth, 2018). Thematic analysis followed six steps, namely: familiarisation of data, generation of initial codes, identifying mutually exclusive and inclusive categories, discovering themes, reviewing, defining and naming themes throughout the data analysis process.

Once participants’ perspectives were identified, meaning was constructed from these perspectives through inductive analysis. Preliminary interpretation of data from the first interview was verified through member checking with the various participants, at the end of the second interview. However, the main aim of this interview was to allow participants to talk about the photographs they brought.

PEI allowed for continuity between the first and second interviews as it offered a tangible reminder of the discussion conducted in the previous interview and facilitated a ‘full flow’ of conversation (Mitchell, 2008: 369). Participants brought 10 to 50 digital images on their cell-phones to the second PEI. Assent for the pictures taken was obtained from the children involved. The photographs acted as prompts, encouraging participants to describe how they facilitated their child’s engagement in occupations including the hindrances they had to overcome and facilitators that enabled them to do so (McCloy et al., 2016; Mitchell, 2008). At the end of the PEI, all the mothers were asked to select three favourite pictures.

Data were analysed with the same process as that following the first interview. Interpretation of data was verified through member checking with the various participants in a final meeting. Data were supplemented by observations and reflections the researcher made in a journal following each interview and during the rest of the research process.

Role of PEI in Uncovering Themes

Two themes emerged in the way that mothers facilitate their children’s occupational engagement. Mothers facilitated the occupational engagement of their children with FASD by doing together, grading their involvement in their doing together, by being flexible in their expectations of their child, and lastly, by involving others in the support for their children. These categories were embedded in the first theme of doing together and underpinned the findings of the study. The second theme of varying access to engagement described how mothers assist in either creating, maximising or limiting access.

PEI played an important role to uncover these themes and categories. Photographs helped participants identify their priorities; for example, when asked to select three favourite images, two of the three images selected by a participant included images of her child helping her. In one image, her child helped her wash clothes by hand and in another, with the cooking. She was thrilled that her child freely joined her in these occupations. Her child’s free choice to join her mother combined with the importance it held to the mother underlined the first theme of doing together:
Interviewer: Tell me why it’s such a special photo?

Participant: There I was together ... I was washing and then she came and then she came to help me to wash.

The researcher reflected upon the unfolding of this theme in the following quote from her research journal:

She obviously enjoys the simple, ordinary chore that she shares with her child. I expected her to go through the motions of a chore like this as quick as possible, and then enjoy 'quality' time with her child... maybe the ball game she also told me about. Yet, this chore becomes their quality time! What a surprise, I must explore this idea.

In contrast, two mothers struggled to describe occupations they shared with their children, but the PEI illustrated occupations that these mothers expressed concern about. Once again, it was photo images that opened the door to these conversations. Images included one participant’s adult daughter next to her home (sitting, according to her mother, for hours in the sun doing nothing) and another’s adolescent son playing a game of chance with friends. When analysing the data the counter evidence – a lack of shared occupations in the presence of occupations raising concern – became evidence (Lincoln, 1988) supporting the theme of doing together.

Images also revealed the process of mothers’ facilitation of occupational engagement. Some pictures illustrated mother and child working together, while other images demonstrated the child engaging in the same occupation alone. Different photographs illustrated the way participants seemed to downgrade their involvement in the doing together from direct to indirect involvement in the category grading involvement, nested in the theme of doing together. This grading is well illustrated by the quote below taken from a description of different images of mother and child with their laundry:

Participant: I fold and then she folds the small things … and I pack it away … [point at the photo] … There they [child and her friend] took the washing down. That line is a little lower....

There they have gone inside and put it on the couch … Then I will come and tell her to fold the small things and I will fold the big ones.

The category involving others, in the theme doing together was similarly illustrated during the PEI, where images showed friends, siblings and extended family such as grandmothers and neighbours. The absence of fathers in any of the photographs was noticeable.

The theme doing together underpinned the findings of the study, while a second theme, varying access, described how mothers fostered the child’s occupational engagement by either creating, maximising or limiting access to various occupations.

In the theme varying access, the category creating access unfolded during the PEI. Here, images such as the family before and at church illustrated the real-life experiences, which children later act out in fantasy play, for example, one boy’s make-believe preaching. It also illustrated the prominence of faith-based organisations in the category involving others in the theme of doing together: for example, singing in a choir or leading a Sunday school class. The following quote demonstrates a young boy’s fantasy play as a preacher:

Zelda: They often play church around the house … He is the pastor [laughing]…

Interviewer: And who is his congregation?

Zelda: Oh, just the tjommies1, he does not name them. He just plays church … and in the house, he preaches to us too… He teases me. When I have been out, he will say: “My mother! You know you should not go out so much!” Especially when he sees me stressing [smiling].

A few participants mentioned a ball game, and the PEI demonstrated children’s ability to play within their limited resources, as well as the way mothers facilitated play by creating access to equipment. Some children used empty tins that their mothers saved from the kitchen as a target in this ball game. Another participant’s child played a similar game although the target this time became stacked bricks. The game and rules were thus adapted to the resources available. Mothers facilitated play by creating access to toys which they bought when money was available or by re-using household items. Children also improvised with the little that was around them. PEI exposed a deeper level of understanding of play and the way mothers facilitate play. A photograph of a young girl with her make-believe baby made a permanent impression upon the first author. The girl carried a cement brick wrapped in a thick blanket on her back. Later, during the same PEI, a photograph of mother and daughter cooking together, while the mother carried her baby in the same way, illustrated that the girl’s symbolic play was a copy of her mother’s behaviour. In the absence of a doll, the girl’s symbolic play brought a brick into her fantasy world.

The final category nested in the theme of varying access was limiting access to describe the way mothers denied their children access to undesired occupations as a way of discipline. One participant disapproved of the game of chance (gambling) her son engaged in because it often resulted in physical fights. Although she grudgingly tolerated her son and his friends playing a fantasy version of the game with small stones, she destroyed their equipment by squashing the tin as soon as they used real coins. This discussion was also triggered by an image during a PEI:

Look! [pointing at the photograph] – Pretend gambling [uncomfortable laugh]... I don’t like that kind of play. It is dangerous, they fight each other. Even the adult men. It is better when they play with stones. That is not money. If he plays that, I don’t want it.... I have already stood on the tins to squash it.
In this way, the images mothers brought to the PEI triggered animated, detailed discussion of both the positive and undesired occupations their children engaged in, as well as the ways they were facilitating children’s occupational engagement.

**Strengths and Limitations**

The study adds a unique lens to viewing the way mothers facilitate occupational engagement of children with FASD, using PEI. This method encouraged the voice of participants often marginalised by stigma. Irrespective of the way participants obtained photographs, PEI emphasised mothers’ expert role in raising their children while the researcher’s previous role of ‘expert’ as therapist faded into one of a student learning from participants. Unfortunately, children could easily be identified in all the photographs. In light of stigma associated with FASD, the researcher had to refrain from publishing images.

Participants emerged as effective facilitators to engage their children in occupations of leisure and self-care, but their facilitation of occupations of productivity reached only as far as domestic chores. Their strength in domestic chores confirmed findings by Jirikowic et al. (2008). The research revealed little of children’s (especially the adult children in the study) engagement in occupations of productivity outside the home, such as income generation. High levels of unemployment in the research site complicated this matter further.

Two of the participants were drinking heavily at the time of the study. These were the same participants who had little to say about the way they facilitated occupational engagement of their children. Participant observation may reveal more about the culture of drinking in these participants’ immediate neighbourhood. A deeper study would be required to explore the factors limiting these participants’ occupational repertoire (Cloete & Ramugondo, 2015) and the way that it impacts their children’s occupational choice (Galvaan, 2015).

FASD may become a generational phenomenon when women with FASD drink alcohol and produce children who are also on the spectrum of foetal alcohol disorder. In this study, one of the adult children with FASD had a young baby of her own. She participated in an FASD prevention programme during her pregnancy and abstained from alcohol. With the grandmother’s help, her baby of 12 months at the time of the research was developing well and playfully engaging with her mother. However, future engagement in occupations of productivity (such as schoolwork) as the child matures may potentially be impacted. The study did not reveal information regarding people with FASD’s engagement in the occupation of mothering beyond caring for a baby.

**Conclusion**

Photo-elicited interviews emerged as a promising method to promote agency of the participants. Images became a door to conversation, helping participants prioritise what they wanted to share. Cell-phones and cell-phone cameras were readily available, even in under-resourced communities, opening possibilities for PEI to be used as a data collection method. Visual images added a deeper layer to the verbal data gained via semi-structured interviews. In this way, mothers raising children with FASD, who are often stigmatised, were able to express their expertise in raising their children with FASD, allowing the researcher to learn from them and describe their contributions towards the development of their children with FASD by simply doing together.

**Acknowledgements**

The first author would like to thank FARR for access to study participants and support during the data collection. This work was financially supported by the Mary Slack and Daughter Foundation.

**Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding**

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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**Note**

1. A local term for friends.

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