Conducting Research With an Adolescent Diagnosed With Fragile X Syndrome

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Abstract: In this article I address the reflexive nature of research undertaken when I investigated the presence of resilience found in an adolescent girl diagnosed with fragile X syndrome. The highlights of this article include specific challenges I experienced when conducting research with this adolescent and how I have adapted the process accordingly. These challenges involve the planning and preparation before data commenced; the influence of sensory integration, behavioral, cognitive and language characteristics of fragile X syndrome on an adolescent girl; and the aspects of ethical and rigorous research. I have also included recommendations such as guidelines for other researchers interested in conducting a similar study with adolescents affected by fragile X syndrome. I hope that with this article, other researchers would be provided with a better understanding of how to proceed with research that involves individuals with disabilities and more specifically, individuals diagnosed with fragile X syndrome.

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1. Introduction

Fragile X syndrome (FXS) is the most common genetic disorder causing intellectual impairment (BAILEY, HAZLETT, ROBERTS & WHEELER, 2011; LEIGH, HAGERMAN & HESSL, 2013) and is associated with multiple, rigorous challenges including physical, emotional, behavioral and cognitive difficulties (BAILEY et al., 2011; HAGERMAN, 2000; HARRIS-SCHMIDT & FAST, 2004; REISS & HALL, 2007). Such a disorder is a challenging condition for individuals and families living with the syndrome, as well as for researchers who want to work with young people with FXS. [1]

Qualitative research has been used successfully in studies of young people with disabilities (CALDWELL, 2014; EAST & ORCHARD, 2014; FENGE, HODGES & CUTTS, 2016; FOURIE & THERON, 2012; SCHELBE et al., 2015). Even though qualitative research is a feasible method of working with young people who have a disability, only a few articles indicate the process of such studies (DeROCHE & LAHMAN, 2008; FRASER, 2015; McCARTAN, SCHUBOTZ & MURPHY, 2012; SCHELBE et al., 2015; SINGAL, 2010; VANDER LAENEN, 2009; WICKENDEN & KEMBHAVI-TAM, 2014). For researchers to understand what is entailed by working with such individuals and ensure the same mistakes are not repeated, it is important to report on the processes involved. [2]

Thus, in this article I aim to reflect on the research conducted as part of my doctoral study, focused on using a qualitative research approach when conducting research with an adolescent girl diagnosed with FXS. I aim to share some of the practical and epistemological problems I encountered during the study. I also provide some guidelines on conducting research specifically about adolescents diagnosed with FXS and on the approach suitable for this kind of research. Because FXS features overlap with other disabilities, such as autism spectrum disorder[1] and Williams's syndrome,[2] my suggestions are likely transferable to other disabilities, even though I focus on FXS. [3]

Due to the many challenges associated with the diagnosis of FXS, it is not possible to approach young people with disabilities in the same way as their peers without developmental and other disabilities. It is, therefore, important to document the process used with these individuals. By documenting the process, other researchers are provided with a better understanding of how to go about conducting research involving individuals with a disability—specifically, individuals with FXS. [4]

I begin with an overview of what the research project entailed and describe the approach I followed and the methods used. In the following section, I share my research experiences and how I handled the process. I aim to demonstrate the

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1   Autism spectrum disorder refers to a group of developmental disorders, including a wide range of symptoms, skills and levels of disability. It is a common comorbid condition in people with fragile X syndrome.

2   Williams syndrome refers to a genetic neurodevelopmental disorder. It is characterized by medical problems, developmental delays and learning disabilities.

value of planning and preparing in advance; furthermore, I focus on the influence that FXS specific characteristics have on the research process. I discuss the final lessons learned with emphasis on the implications on ethical aspects and rigor. Throughout, I provide recommendations as guidelines to other researchers. [5]

2. The Research Project

In 2008, I became the live-in carer of an adolescent girl diagnosed with FXS, just after my post-graduate studies in education. Some of my education courses were focused on disabilities and, as a result, I developed a deep interest in working with young people who were challenged by disabilities. I applied to a program to become a live-in carer to a family in the United States. The family I was placed with had a 16-year-old girl, named Lucy (for the purposes of this article) who was diagnosed with FXS at the age of six. Before getting in touch with the family, I had never heard of this syndrome. [6]

Being Lucy's carer entailed assisting her with daily tasks such as choosing outfits and getting dressed; driving her to school and extracurricular activities; helping with homework; organizing social activities; and being present and facilitating social encounters with her peers. Lucy and I spent a lot of time together and became good friends. She came to trust me. She thought of me as her sister. When I would call her on the telephone or greet her, she would reply by saying, "Hey, sis!" [7]

Lucy's parents were members of the National Fragile X Foundation during my time as live-in carer and were, therefore, very involved in the FXS community. Their involvement within this community afforded me opportunities to meet the leading FXS researchers; spend time and interact with some of these individuals; visit their respective institutions and practices; and attend conferences specifically focused on FXS. I was also able to spend time with other children diagnosed with FXS. This allowed me to not only get to know Lucy but also other young people with FXS; thus, I gained a better understanding of the differences between these individuals. These experiences allowed me to not only become a better carer for Lucy but also a better researcher conducting research with an adolescent girl with FXS. [8]

2.1 My research approach

During my time as Lucy's caregiver, I was fascinated with how resiliently she coped with the many challenges of her disability. I began to wonder what would help individuals like Lucy to be resilient despite their living with FXS. I wanted to focus on finding the positive features and her successes within her challenging experiences (MERTENS, 2009). The aim was to generate a perspective of Lucy's situation, to examine her situation, and to comment meaningfully on the ways in which she made sense of her situation (HENNING, VAN RENSBURG & SMIT, 2004; NIEUWENHUIS, 2007a). I, therefore, worked from a transformative paradigm (MERTENS, 2009) and approached the study from an interpretivist perspective (NIEUWENHUIS, 2007a). I interpreted what Lucy told me, but I also

understood that what she told me was her interpretation of reality. With this perspective, I see my work placed in the postmodern realm (ibid.). [9]

I reviewed the literature available on FXS and its characteristics. I often met with Lucy's parents seeking advice to determine and understand her specific characteristics. I also reviewed relevant literature on how to conduct research with individuals with a disability. I found no reports that specifically focused on individuals diagnosed with FXS. According to BEAIL and WILLIAMS (2014), the data obtained from a participant with a disability should not be seen as having any less value than from a participant without disabilities. The extensive time I spent with Lucy was a unique opportunity to collect data from an adolescent girl diagnosed with FXS. [10]

I was cautious about ethical aspects, as the study was focused on an adolescent diagnosed with FXS. Before the study commenced, the ethics board of my university provided ethical clearance. I was meticulous with regard to respecting Lucy and not to cause her physical or emotional harm. I was vigilant about the consent procedure, as I was fully aware that her cognitive impairment could possibly compromise her capacity to consent. [11]

I spent three months building a relationship of trust (GINSBERG & MERTENS, 2009) with Lucy before introducing the possibility of her participation in the study. I cautiously negotiated permission from Lucy and her parents to conduct the study. I first approached Lucy's parents to gain permission and asked them to sign a consent form. I explained to them that I would work from a positive psychology framework (SELIGMAN, 2005), as I would focus on her resilience as opposed to her vulnerability (MERTENS, 2009). They were excited by this opportunity and were eager to help and participate in any way they could. I provided them with the necessary information and asked them to explain to Lucy what the study was about. Once they had done that and Lucy had agreed to take part, I again explained to her in my own words what the study was about and what was expected of her. I tried to keep the terminology simple, to ensure that she understood due to her language barriers associated with FXS. I also communicated slowly and clearly and introduced the concepts one point at a time. I asked if she had any questions and if there was anything or any part that she was unsure of, so that I could explain it again. She had no questions. I then provided Lucy with informed consent forms for her to sign. Lucy's parents were also asked to explain the consent forms and their contents to her, to make sure that she fully understood. [12]

I also provided the secondary participants with comprehensive letters of information as well as consent forms. Their participation was voluntary, and they were made aware that they could terminate their participation at any time. None of the participants' real names was used. [13]

2.2 Methods

I used qualitative, single case study design, as I regarded my live-in proximity to Lucy as an ideal opportunity to explore and understand the factors that contributed to her coping resiliently with the daily challenges of living with FXS. The credibility of the study was heightened by my prolonged engagement with Lucy and her family, as I was able to develop a rich, saturated understanding of her resilience (MERTENS, 2010). [14]

Convenience sampling took place, as I was a live-in carer to Lucy, the participant (HENNING et al., 2004). Because convenience sampling has been found not to be very credible (MERRIAM & TISDELL, 2016) and because my opinion of Lucy's resilience might have been biased, an advisory panel (AP) was appointed to comment critically on Lucy's apparent resilience and to verify if they indeed saw Lucy as resilient. An AP refers to members of the community who have access to and knowledge of local young people who are resilient despite difficult lives. The use of an informed AP is advised and modeled by UNGAR, BROWN, LIEBENBERG, CHEUNG and LEIVNE (2008, see also DIDKOWSKY, UNGAR & LIEBENBERG 2010; UNGAR & LIEBENBERG, 2011). The AP consisted of three individuals within the FXS community: a psychologist, a teacher and Lucy's mother. I interacted with the AP to reach consensus on a definition on resilience. After we agreed on a definition, the AP was unanimously confident that Lucy was resilient. I also invited secondary participants who contributed to my understanding of Lucy's situation and resilience. These participants included her mother, a former primary school teacher, and her current tutor. [15]

The data collection methods that were used included *in situ* observations and interviews. I observed Lucy for over 20 months and recorded the observations in a reflection journal (MERRIAM, 1998), as well as visually in the form of photographs and video clips (BOGDAN & BIKLEN, 2007). Because of Lucy's language difficulties and anxiety with regard to social interaction, I interviewed her informally. These informal conversations (MERTENS, 2010) included open-ended questions and much probing (PATTON, 2002). The study time was limited, as I was only allowed a two-year period in the United States. [16]

Semiformal interviews were used to interview the secondary participants (MERRIAM, 1998). This form of questioning enabled the secondary participants to share their understanding of Lucy's resilience. I asked all the participants the same questions and their responses were probed by asking for examples or more information. [17]

I primarily used inductive qualitative analysis to organize, code, and categorize the data collected (CRESWELL, 2007; MAREE & VAN DER WESTHUIZEN, 2007; NIEUWENHUIS, 2007b). One data set (i.e., the transcribed interviews, the research journal, or the visual data set) was coded at a time (CRESWELL, 2009). This meant that I labeled each section of the data that answered the guiding research question, "What contributes to positive adjustment in a young woman with FXS?" The codes were influenced by what I understood about resilience and

FXS, as well as my experience as Lucy's live-in caretaker. Therefore, although my primary approach was inductive (as I looked for issues within the data that shed light on how young women with FXS coped resiliently), some deductive coding was also present (MERRIAM, 1998), as I looked for issues within the data that shed light on women with FXS coping resiliently. A combination of inductive and deductive coding is common to analysis (CRESWELL, 2009). Thereafter, I grouped similar open codes into codes that identified the resources operating protectively for Lucy, before comparing my coding. This was an iterative process, which I repeated per data set and then across data sets. [18]

The emerging codes from all three data sets were consistent; therefore, I was able to triangulate my emerging analyses. Although this consistency of findings are insufficient to address the limitations of a single case study or enhance trustworthiness (MERTENS, 2010), the triangulation was useful in seeing an "in-depth picture" (CRESWELL, 2007, p.76) of Lucy's resilience and the descriptions of the resilience promoting resources. [19]

I used peer debriefing to ensure trustworthiness, by reviewing and discussing the research process and findings with unbiased colleagues (SHENTON, 2004). To ensure the credibility of the findings I confirmed with the participants if what I understood was correct (LINCOLN & GUBA, 1985; MERTENS, 2009). The literature review was useful in that I was able to apply logical reasoning and interpretation of the data collected (SHENTON, 2004), and the contextual information provided of Lucy facilitated transferability. I also included direct quotations from the conducted interviews. I regularly engaged in reflexivity and recorded my developing arguments, feelings and interpretations in a research journal. Such discipline allowed me to reflect on my situatedness in the study. Although this does not nullify the limitations of case study methodologies, the working hypotheses that emerged from the study were useful in guiding transferability. [20]

In the following section, I share my experiences of conducting research with an adolescent girl diagnosed with FXS, the manner I handled the process, and my recommendations to other researchers who might find themselves in similar situations. [21]

3. Planning and Preparing

Before embarking on any research project, sufficient planning and preparation should be done, even more so when the focus of the research is on individuals with a disability such as FXS. As stated earlier, before any data collection took place, I had read extensively on FXS. I interacted with Lucy's parents and professionals in the field, attended conferences and lectures. This allowed me to be fully aware of Lucy's characteristics and furthermore provided me with the knowledge on how to handle certain situations that emerged during the research process. By means of observations, I was also able to understand Lucy better and learn from these experiences and occurrences and plan the research process accordingly. An illustrative example was recorded in my research journal:

"Lucy's mother had an errand to run today and she saw it as an opportunity for Lucy to get out of the house. She discussed the plan with Lucy, explaining exactly which store we would visit, which road we would travel on to get there, and what the reason was for visiting the store. Lucy agreed to go along. Once we arrived at the store, Lucy refused to get out of the car. Her mother insisted that she get out and again explained to her the plan and reminded her that she agreed to come along. Lucy experiences so much anxiety that she started screaming and hitting her mother. Later on that day, Lucy told me that she saw a friend from school in the parking lot outside the store. I then understood that she had become so anxious due to social anxiety that she was prone to and at that moment she had been unable to explain to us why she could not get out of the car" (Research Journal, March 17, 2009). [22]

PROSSER and BROMLEY (2012) recommended to systematically introduce yourself as the researcher before starting with any form of research. My situation as live-in carer allowed me the opportunity to build a relationship and become a close friend to Lucy before any data collection took place. I was able to gradually and systematically explain to Lucy that I was conducting a study on FXS. An example that illustrates this was taken from my research journal:

"During our drive home from school, Lucy asked me how my day was and what I did while she was at school. I explained to her that I visited the library to read up and learn about FXS. Lucy explained to me that it was 'her syndrome' and that she would be happy to talk to me about it anytime I wanted (without me asking her to take part). I then informally introduced her to the study and told her what it was about" (Research Journal, April 7, 2008). [23]

This introduction to the study was done before any formal explanation and procedures took place. My situation was unique and I realized that it might not be possible for all researchers wanting to conduct research with an adolescent diagnosed with FXS, as I was able to study this issue. Therefore, I would like to provide the following recommendations for other researchers to consider. [24]

Recommendations

- Read up as much as possible on FXS before conducting research with a participant diagnosed with the syndrome.
- Spend enough time in the field to get to know the participant before any data collection takes place.
- Engage with the experts in FXS. Even if a researcher is very familiar with the participant, it is still a good idea to be as well-informed as possible, based on objective scientific knowledge and the advice of others who know the participant well.
- Provide the participant with a slow introduction to the study. [25]

4. The Influence of Specific Characteristics

Each individual with FXS is different. Even when the individual exhibits the same characteristics, major differences may be present to some extent which they display them and the extent to which they affect the individual's ability to function (HARRIS-SCHMIDT & FAST, 2004). Even so, specific characteristics are associated with FXS. Some of which may have manifestations among a significant number of individuals and many which will be recognized by those who are familiar with people who have the syndrome (SAUNDERS, 2000). These include sensory integration, behavioral, language, and cognitive developmental issues. In the following section, I discuss the influence that these characteristics of FXS have had on the research process. Furthermore, with such influence, I aim to demonstrate how I was able to structure my reflections. [26]

4.1 The influence of sensory integration

Individuals diagnosed with FXS have difficulty interpreting information absorbed through their sensory systems and this can affect their overall functioning (BRADEN, 1996). These sensory integration difficulties can interfere with their speech or language, behavior, and cognitive development, so that integration thereof is important for their overall functioning (ibid.), as this affects the research process. With the knowledge I gained from reading up on FXS, I learned to be extra cautious of the setting where an interview took place. I recorded the following in my research journal:

> "I took Lucy out . . . for coffee today. There were no customers inside the shop, which would decrease her anxiety about the situation. Inside the shop I attempted to have a conversation with her, but she wasn't able to answer any basic questions I had for her. She seemed so nervous and kept asking me if I didn't think it was time to go" (Research Journal, March 13, 2009). [27]

The loud noises and the possibility of seeing someone she might know, caused her to become anxious. Because of this observation, I considered carefully where the interviews between Lucy and I would take place. [28]

Many individuals with FXS have difficulty in making direct eye contact with others for more than a few seconds. They typically feel overwhelmed and the reason for this may be that direct eye contact involves too much visual information for them to process (BRADEN, 2002; HAGERMAN, 2000). The following was recorded in my research journal:

> "We have specific places where we sit at around the dinner table each night. I was [sat] next to Lucy. Her mother explained to me that Lucy has difficulty making eye contact, especially with people she is unfamiliar with and therefore has found it best for me to sit next to her to allow her to feel less anxious" (Research Journal, February 5, 2009). [29]

In subsequent informal conversations, I was careful not to sit opposite Lucy. Furthermore, it was also important for me to pay attention to what I was wearing when interacting with Lucy. It has been found that certain fabrics and types of clothing can bother individuals with FXS (HAGERMAN, 2000; HARRIS-SCHMIDT & FAST, 2004). I recalled a time when I wore a blouse, which made her extremely uncomfortable, so much that she was unable to follow any tasks. The blouse had two layers; the inner layer was plain cotton material, with a layer of crocheted flowers. She kept insisting that I change into something different. I recorded the following in my research journal:

> "Today I wore a new blouse that I bought last week. It has a pattern on it that Lucy doesn't like. Even though she did not even touch it, I was not allowed to come close to her. She kept asking me to please go and change my blouse" (Research Journal, April 5, 2009). [30]

Recommendations

- It is advised that the data collection (specifically interviews) be done in a setting that is quiet, comfortable and familiar to the participant.
- Try to make as little as possible direct eye contact with the participant, to eliminate additional anxiety.
- Be cautious of what clothing you as researcher wear during interaction with the participant. Do not wear any turtlenecks or materials that have a pattern, sequence or crochet work on it.
- Do not make unnecessary physical contact with the participant, for example trying to exchange a hug, or a rub on the shoulder. [31]

4.2 Behavioral characteristics

Individuals diagnosed with FXS have a high frequency of avoidant behavior, mood disorders, attention deficits and learning disabilities (BRADEN, 2013). They also often experience a great degree of anxiety, which can result in severe panic attacks that directly affect their daily functioning (HAGERMAN, 2000). These individuals often develop fear of the situation or environment in which the anxiety was experienced, and the need to avoid any similar experiences in the future (BRADEN, 2002). Often, Lucy's inability to tolerate certain input resulted in challenging behavior, as was found when asked to run errands with her mother (see Research Journal extract from March 17, 2009). [32]

It was important to determine the frame of mind Lucy was in before an interview could be conducted. Daily experience of interacting with Lucy made me aware that she was not able to take part in the research process if she had, for example, a bad day at school or did not have a good night's rest. This might be the case with a participant without disabilities. However, it is more complicated for individuals with FXS, as they have more difficulty adjusting their behavior than others (BRADEN, 2013). An example is as follows:

> "Every day after school I would ask Lucy how her day was at school. She would either reply by saying 'good' or 'OKAY'. I now have learned from experience that when she answers 'good' to the question she is in a good mood and had a good day at school. When she answers 'OKAY' something happened at school and was bothering her. Later that evening she would tell her mother that she is not feeling well and that she does not want to go to school. And after a long discussion her mother would get behind what really bothers her and what exactly happened at school that day. I learned from this that it is best not to try and conduct an interview on these days" (Research Journal, August 9, 2008). [33]

Individuals with FXS have a strong desire to interact with others. Anxiety, hyperactivity, impulsiveness and even a short attention span make it difficult for these individuals to socialize. Furthermore, their hyperactivity and attention deficit may result in excessive motion, difficulty staying still, which can contribute to difficulty staying focused and attending (BRADEN, 2002). Lucy had a short attention span and was found to have attention deficit. These characteristics affected her ability to stay focused on the questions asked during the interviews. I demonstrate this with an extract from an interview:

> Myself: "Can you tell me more about fragile X syndrome?"
>
> Lucy: "I have a special syndrome."
>
> Myself: "What is it called?"
>
> Lucy: "It is on my shirt."
>
> Myself: "Fragile X?"
>
> Lucy: "Nods (yes)."
>
> Myself: "Wow! OK, so what is fragile X? I know it is your syndrome, but can you give me an explanation?"
>
> Lucy: "Fragile X to me is ... ummm ... (a 5 second pause) I get to see ummm the people."
>
> Myself: "What people?"
>
> Lucy: "In California."
>
> Myself: "Oh, you mean the researchers at Stanford University?"[3]
>
> Lucy: "Yeah ... and then like, the like, ummmm, ummm, you go to parties. And it's really fun."
>
> Myself: "Yes, the parties are fun. What can you tell me about fragile X? How does it affect you?"
>
> Lucy: "I was diagnosed in March. And I wear glasses." [34]

Lucy often modified her behavior by talking about unrelated things. She also enjoyed role-playing (pretending to be someone else). Furthermore, I was able to

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3   Stanford University is a private research university in California, USA. Lucy's brother, father, grandfather, and grandmother attended Stanford University. Although Lucy was not able to attend the university like her family members, she was involved in a study at the Center for Interdisciplinary Brain Sciences Research at Stanford University. Being able to participate in research made her feel that she has continued (in her own special way) the family tradition of attendance and participation at the institution.

ask Lucy direct questions, as we already had an established relationship and I was aware of what would make Lucy feel uncomfortable or ashamed. Lucy was proud of being part of FXS, and her parents raised her this way. So, I knew in advance that asking her about FXS and how it made her feel would not be harming her in any way. After an interview, I thanked Lucy for taking part in the interview and for providing me with such valuable information. Her reply was as follows:

> Lucy: "Anything else you wanna tell me? Anything. Any celebrities you want to ask me?"
>
> Myself: "Have you met any celebrities?"
>
> Lucy: "Ummm … I met Tom. Tom Chapin."[4]
>
> Myself: "Wow! Has he helped you with fragile X at all?"
>
> Lucy: "Ummm ... he doesn't even know that I have it. He helped me ... he helps me by not being shy to people."
>
> Myself: "That's awesome! How did he do that?"
>
> Lucy: "Because I met his daughter."
>
> Myself: "So how did you meet?"
>
> Lucy: "Ummmm … YouTube."
>
> Myself: "So do you ever speak to her?"
>
> Lucy: "I listen to her music."[5] [35]

My research journal furthermore allowed me to record the kinds of activities that took place:

> "She talks to herself in the bathroom and pretends to talk to people at school and sometimes even celebrities. Today I asked her who she was talking to and she replied, 'Nobody, just myself', and I asked her why and she replied 'I'm practicing' " (Research Journal, May 5, 2009). [36]

Because I interacted with her informally, I was able to observe her behavior as it occurred in her natural setting (MERTENS, 2005) and I was able to understand the context better. [37]

Recommendations

- Do not prepare a participant too far in advance, as the individual might become so anxious about the event; that obsession over the change will overshadow the benefit of prior preparation. Simply provide more indirect interventions (such as side-dialogue between the parents) a day before.
- Be conscious of developing strategies to reduce anxiety the participant might experience, for example, step-by-step planning. The participant will feel

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4   Tom CHAPIN is a popular American children's entertainer.

5   Tom CHAPIN's daughter appeared on a series of records for children that Tom CHAPIN recorded as she was growing up.

comfortable and safe if she knows exactly what would happen during the research process and this may decrease anxiety.

- Due to the individuals' short attention span, repeat questions as many times as needed during an interview.

- Provide opportunities for flexible breaks and ensure that interviews do not last too long. Rather, have more than one interview, than one tedious interview. [38]

4.3 Language characteristics

In most cases, the vocabulary and grammar skills of young women diagnosed with FXS are age-appropriate. However, they may have difficulties with pragmatics (BENNETTO & PENNINGTON, 2002; HAGERMAN, 2000) or the arrangement of words and phrases to make sense (ABBEDUTO, BRADY & KOVER, 2007). For example, the individual might say something inappropriate; she might talk about unrelated things; tell stories in a disorganized way; and have little variety in language use. She may find it difficult to express herself. Therefore, having a conversation with others is a difficult experience for these young people. This would obviously affect the data collection process. When the individual with FXS is put on the spot, anxiety often arises and she is unable to give appropriate feedback (BENNETTO & PENNINGTON, 2002; HAGERMAN, 2000). A typical conversation would be as follows:

> Myself: "What is your role in this year's school play?"
>
> Lucy: "I wore a purple dress in freshman year."
>
> Myself: "Lucy, what is your role in this year's school play?"
>
> Lucy: "This is my last play. Next year I'm going to help backstage. This is my last play."
>
> Myself: "The name of your play this year is 'Oklahoma!' right?"[6]
>
> Lucy: "Yeah."
>
> Myself: "What is your role again? Who are you playing?"
>
> Lucy: "Umm, umm, I'm Vivian."[7] [39]

Individuals with FXS also tend to perseverate when they speak. An example of perseveration can be that the individual with FXS might ask a question many times, even after the answer has been given. This can happen in an interview, and the researcher should be aware of the characteristic, as it may bother people who do not understand that this is a typical feature of individuals with FXS (HAGERMAN, 2000). [40]

Their social anxiety and shyness may get in the way of communicating. Lucy often avoided questions or had difficulty interacting socially, because she either did not understand the question or did not know how to respond appropriately. She had difficulty expressing herself. She often responded to questions with

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6   Oklahoma! is a musical written by Richard RODGERS and Oscar HAMMERSTEIN II.

7   Vivian is a character in the musical play Oklahoma!

inappropriate or unrelated answers. For example, Lucy had difficulty acting appropriately around the opposite sex. During a conversation, I wanted to know from her what her school has done to help her cope resiliently. She replied, "This is my fourth year." To some this might seem as unrelated, but because I knew Lucy well I understood that she was actually leading me. She just did not have the ability to express herself and, therefore, needed more probing. Earlier that same week, Lucy's mother told Lucy that she needed to act more appropriately, as this was her fourth year at the school. I overheard this conversation and was, therefore, able to lead Lucy to obtain more information based on the knowledge I had of the situation. If the researcher is unaware of the language characteristics of an individual diagnosed with FXS, little information will be obtained from the participant. [41]

Recommendations

- Certain behavior such as hand flapping might occur whenever the participant becomes anxious. Be cautious of creating anxiety, and react immediately to the warning signs by allowing the participant to be excused from the activity or to change the activity as needed.
- Become as familiar as possible with participants' language characteristics.
- Use informal conversation with the participant as data collection strategy, rather than informal interviews.
- Be cautious of your language use as researcher and choose simple words.
- If possible, have an involved adult explain to you as researcher a situation or event that emerged in an interview. The involved adult might have more insight into the situation.
- Use probing and leading questions when necessary to enable the adolescent express herself.
- During follow-up interviews, attempt to find more information on what was unclear in the previous interview. [42]

4.4 Cognitive characteristics

FXS affects individuals' cognitive development in many ways. Their biggest struggles relate to abstract reasoning as well as formulating and executing a plan. Long-term memory is strength within these individuals. As cognitive development refers to thinking, problem solving, conceptual understanding and information processing, it can be said that attention problems could directly have an impact on how the participant understands the researcher and the questions asked, as well as on how the participant responds to what is asked. [43]

Initially, my intention was to have a semistructured interview with open-ended questions, as recommended by literature, as this has been found to be the most appropriate way to get the most information from a participant (PROSSER & BROMLEY, 2012). However, I found that this was not always possible with Lucy. I often ended up using informal conversations and using leading and close-ended

questions. This posed as a limitation, as it often directs the participant in a narrow or biased way, depriving her of the chance to articulate her experiences in her own terms. Although individuals with FXS have a strong desire to interact, their anxiety, hyperactivity, impulsivity and short attention span make it difficult for them to interact with others (HAGERMAN, 2000). I did, however, use an interview schedule as a guideline. It is important as researcher to be aware of and familiar with the participants' abilities in terms of what they say, and also to state the questions carefully (ALDRIDGE, 2014; BEAIL & WILLIAMS, 2014). I also used photographs, video clips, a research journal as well as multiple secondary participants to collect data, to ensure that what I found during the informal conversations could be verified. [44]

Recommendations

• Use various research instruments to ensure trustworthiness and credibility.
• If necessary, repeat questions during the interviews for the participant to stay focused.
• Individuals with FXS have excellent long-term memory. Where suited, use this positive feature during research. [45]

5. Ethical Aspects

Researchers should be extra cautious of the ethical issues relating to participants with disabilities (ALDRIDGE, 2014). However, like any human being, individuals with intellectual disabilities have the right to decide whether or not to participate any research (FREEDMAN, 2001). McDONALD and KIDNEY (2012) argued that the lack of ability should not be the motive for an individual to be excluded from participation. As with any participant, attention should be paid to the following aspects discussed. All research that involves young people as research partners should take care to ensure that participation serves the interests of the individual child or adolescent (AKERSTRÔM & BRUNNBERG, 2012). [46]

5.1 Avoidance of harm

It is important to remember the possibility that an individual could potentially become distressed when a previous traumatic experience or uncomfortable memories are recalled (HALL, 2013). Lucy was never harmed in either a physical or an emotional manner. In most instances, she was keen to participate. I always tried to keep the interviews short to ensure that Lucy did not tire, was able to stay focused and for it to be a positive experience. After an interview, I thanked her for taking part and she replied as follows:

Lucy: "Anything else you wanna tell me? Me!!! Ask me!!"

Myself: "You want me to ask you more questions?"

Lucy: "Yes. Anything."

> Myself: "You just love being interviewed, don't you?"
>
> Lucy: "Absolutely! (laughing) Ask me anything!" [47]

I was continuously aware of the fact that she might experience traumatic or uncomfortable memories; therefore, her mother was always nearby to provide the support that Lucy might need. An educational psychologist was informed of the research I was conducting with Lucy and she offered her services as needed. [48]

5.2 Electronic recordings

Electronic recordings have been found to increase the rigor of the data collected, as the researcher is able to go back and check, clarify and audit what was said by the participant (McVILLY, STANCLIFFE, PARMENTER & BURTON-SMITH, 2008). It is important to continuously consider how the participant feels about the interview being recorded, as some may find it intimidating. I was aware that my dual role as live-in carer and researcher might be considered intrusive (LEEDY & ORMROD, 2005; NTSEANE, 2009). I dealt with the aforementioned limitation by using a voice recorder, as Lucy, her parents, and I agreed that the use of a voice recorder would clearly signify when a formal research activity would take place. [49]

Before any conversation was recorded, I explained to Lucy that our conversation would be recorded, for me to remember what she said. I then again explained to her what the reason was for me to have this conversation with her. This was not daunting to her, but on the contrary, it created a sense of pride within her to know that she was partaking in an important study about "her syndrome" as she referred to it. Before every interview, I started by explaining to her that the recorder would now be switched on and again when it would be switched off. This was a practical explanation to inform her when research was to be conducted and when research conduction was done (FOURIE & THERON, 2012). [50]

5.3 Deception of participants

Research processes should follow clear ethical principles and processes by checking back after each data gathering activity. To prevent deceiving Lucy, I was honest about the goal of the study. Recognizing Lucy's language barrier, I was careful to explain matters to her in simple language and to check whether she understood. What was expected of Lucy was also explained openly to her. I interviewed her, observed her in her natural setting, and collected visual data such as photographs and video clips to back up what I observed. I carefully explained to her the emotions, such as uneasiness that she might go through should she remember previous experiences that had been unpleasant.

> "A week after our first interview, I asked Lucy about a situation she explained to me about having a fear of dogs and how she coped with overcoming these fears. I was aware that she still had some fear of dogs with which she was not familiar. I asked her if she was at all feeling anxious about dogs and if she had nightmares etc." (Research Journal, August, 13, 2008). [51]

After each consecutive interview, I also informed the aforementioned educational psychologist about the possible negative emotions Lucy might experience recalling events in the interview. She was also able to monitor Lucy's emotions during their weekly sessions. [52]

5.4 Violation of privacy

The right to privacy is the individual's privilege to decide when, where, to whom, and to what extent her attitudes, beliefs, and behavior will be revealed (STRYDOM, 2005). There has been extensive discussion regarding the consenting capacity of people with intellectual impairment (DYE, HARE & HENDY, 2007; FISHER, CEA, DAVIDSON & FRIED, 2006; FREEDMAN, 2001; IACONO & MURRAY, 2003; INGLIS & COOK, 2011; TAUA, NEVILLE & HEPWORTH, 2014). It has been assumed that people with intellectual impairment do not have the capacity to understand and, therefore, are unable to give consent. However, those with intellectual impairment should never be assumed incompetent based on their intellectual impairments. According to FREEDMAN (2001), the decision to participate or not should be individualized according to the context. People with intellectual impairment have the same rights as all others in regard to choosing whether or not they wish to participate in research. What is important is that all information and documents are provided at the appropriate level for each person to understand. Therefore, the first assumption should always be that the person has the capacity to consent. [53]

I aimed to empower Lucy by allowing her to have as much control as possible over her participation (CALVELEY, 2012). I used clear and simple language, which was meaningful to Lucy to explain the study and her role in the study. Her parents also helped Lucy to understand by using terminology familiar to her. Following verbal explanations, Lucy was provided with written information. I extended the consent process with Lucy by verifying consent at different times throughout the data collection process (SCHELBE et al., 2015). Gaining consent was viewed as an on-going process. I continued to remind Lucy that she could withdraw from the study at any time; I also provided her with concrete examples of how to communicate this to me, for example, "Just say, please stop." [54]

I assured Lucy that her name would not be used to ensure no easy identification. Nevertheless, she was happy to pose for photographs and to be videoed. I never recorded events where she would be portrayed negatively. I assured her that if there were information she wished not to share, I would not include that in the study. I explained to her that she did not have to answer the questions that I would ask her during the study, but that the more questions she was able to answer, the better the results of the study would be. I realized the importance of how to obtain consent, provide accessible study information if the participant lacks capacity to understand such information (TUFFREY-WIJNE, BERNAL & HOLLINS, 2008). [55]

An educational psychologist was employed as a "research advocate" (SCHELBE et al., 2015, p.515), who met individually with Lucy on a regular basis. During

their meetings, she would ensure that Lucy understood the research process and her role in the research, assessing her emotional vulnerability, to process the experience, and provide further follow-up if needed. According to SCHELBE et al., a "research advocate" provides an essential safety net for the participant in keeping with ethical considerations. Furthermore, before using any photographs or video clips I would ask Lucy as well as her parents to have a look at the data, to ensure that they are comfortable with the way the events were captured and for them to once more give their consent in using these documented data in the study. [56]

5.5 Debriefing of participants

Debriefing refers to sessions during which the participant has the opportunity, after the study, to work through her experience and its aftermath (STRYDOM, 2005). After each interview, I had a session with Lucy where I explained in simple language what the study was about and how her answers have helped me in the study. I then asked her if she felt sad about the interview, in simple language. I also asked the educational psychologist to do so during their sessions together. There were no such feelings. [57]

<u>Recommendations</u>

- Involve parents in the process of informing the participant about the research project.
- Search for signs of refusal (subtle or obvious) and ensure no pressure is applied.
- Evaluate evidence of the participant's understanding through simple questions and feedback.
- Use clear and simple language, which is meaningful to the participant.
- Allow adequate time for the participant to think and respond.
- Regard consent as an on-going process. Re-negotiate verbal consent daily, or more frequently.
- Ask questions such as "Are you feeling okay?" or "Would you like to take a break?" during the interview to ensure the participant is still comfortable and not feeling violated.
- Provide the participant with concrete examples on how to communicate that she no longer wants to take part or wants to take a break.
- Once you know the participant's language idiosyncrasies, and it is clear that the participant is unable to participate that specific day, be flexible and postpone the research activity. [58]

6. Rigor

One major limitation was the form of questioning. I often initiated the questions, and, therefore, the credibility of the study could be questioned. To ensure the credibility of the study, I included secondary participants, observations and visual data. After interaction with the participant, I noted down what I had observed (KELLY, 2006) and transferred my written notes to a computer (BOGDAN & BIKLEN, 2007). However, I often had to rely on memory to recall the sessions observed. I had decided to do this as it might have made Lucy nervous or anxious if I continuously made notes. This was a limitation, as I could not always remember the events as precisely as I would have, had I made notes during the observation sessions. [59]

To ensure credibility, I also used reflection, which included actively questioning, raising issues with others (such as the participant's mother) to confirm what I had observed and my understandings of the observations. Aspects that were not or could not necessarily be found or seen during the interviews, because the participant could not express certain things or talk about specific experiences could be noticed during the observations. [60]

Recommendations

• Use various forms of data collection instruments when conducting data with participants with FXS.
• Consider allowing a co-researcher to take down notes during an interview. A co-researcher being present might create additional anxiety for the participant. Thus, an advanced introduction is recommended and that the participant is comfortable with and knows well the co-researcher before any research starts.
• Consider using video recording during observations.
• Reintroduce the study to the participant throughout the research process. [61]

7. Conclusion

Individuals with disabilities are seen as vulnerable participants. According to ALDRIDGE (2014) as well as PROSSER and BROMLEY (2012), certain challenges occur when conducting research with vulnerable participants. Challenges that emerged in my study referred to influence of the participant's sensory integration, behavioral, cognitive and language issues. Additionally, I included the ethical aspects as well as the rigor of the study and how I addressed these issues. This article, therefore, shows a number of ways to approach and conduct research with an adolescent girl who is affected by FXS. [62]

Although this single case study cannot be generalized to all individuals with intellectual impairment or all individuals with FXS, it can serve as a guideline to other researchers considering conducting research with such participants. Research involving individuals who are intellectually impaired should be of high

quality, and the researchers should have the necessary skills and understanding to ensure inclusion and protection. It is recommended that researchers step outside the boundaries relating to conducting research and be more adaptive and creative when involving vulnerable participants. [63]

Acknowledgments

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