

The experience of growing up with a parent with schizophrenia : a qualitative study

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Citation:

NIETO-RUCIAN, Vanesa and FURNESS, Penny (2018). The experience of growing up with a parent with schizophrenia : a qualitative study. Qualitative Psychology. [Article]

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Abstract

In this study, we investigated the subjective experiences of six individuals from Spain who grew up with a parent with schizophrenia. Our objectives were to explore participants' perceptions of the effects of these experiences upon their development and their sense of continuing impact upon their adult lives and relationships. Our approach was guided by Interpretative Phenomenological Analysis (IPA) and data collection involved in-depth interviews with participants. Three themes were generated: Role change and loss, Prison of Silence and Who Am I? The findings highlighted the stigma of schizophrenia in society, a lack of support, emotional deprivation in childhood, and lasting negative effects for these participants upon their world view.

Schizophrenia is a severe mental disorder that affects over 21 million people worldwide, of whom half receive no care for their condition (World Health Organization [WHO], 2016). Symptoms are categorized as *positive and negative*. Positive symptoms include hallucinations and delusions (WHO, 2016), those symptoms are easy to identify and are classified as “psychotic behaviors not seen in healthy people” (Patel et al., 2014), so are “added” to the person’s psyche, which can be treated with medication. Negative symptoms are more difficult to identify, they are characterized by loss or deficits of emotions and behavior that the person had before suffering schizophrenia, include flattened affect, avolition and difficulty in emotional expression (Tandon et al., 2013), which tend to persist, despite medication. Negative symptoms impact caregivers’ lives and may increase their burden (Provencher & Mueser, 1997). Studies have found high levels of burden and impacts on health in family members of schizophrenia patients (Awad & Voruganti, 2008; Geriani et al. 2015; Gutierrez-Maldonado et al. 2005; Ukpong, 2006), and higher risk of developing depression and anxiety, especially among less well educated caregivers (Li et al. 2007; Kizilirmak, Kuçuk, 2016; Magaña et al. 2007). Also, it was found that young people of parents with a mental illness are a significant risk of developing a mental illness (Grove et al. 2016). The effects of having a child with schizophrenia include grief through the loss of an “idealized” child (Tuck et al. 1997; Atkinson, 1994; Davis & Schultz, 1998), alongside stress and guilt, especially in the mother, often the principal caregiver (Milliken, 2001); however, knowledge regarding the experience of and effects upon children of growing up with a schizophrenic parent is lacking.

Attachment is defined as a “lasting psychological connectedness between human beings” (Bowlby, 1969, p. 194). Attachment theory focuses upon the attachment between parent and child, and the effects this bond upon the child’s personality, interpersonal skills, and ability to

form healthy adult relationships. According to Bowlby (1969), parents who are available and responsive allow their child to develop a sense of security, creating a strong foundation for them to explore the world. Problems in parent-child attachment in early life would have negative effects on behavior in later childhood and throughout the lifespan, although others have argued that people outside the parent-child dyad can also impact a child's development and behaviour (Field, 1996; Harris, 1998). The lasting effect of childhood attachment problems is highlighted in recent studies which link them to difficulties with trust and intimacy and, therefore, in forming secure adult relationships (Cucu-Ciuhan, 2015; Duncan & Browning, 2009).

Negative symptoms in schizophrenia, such as difficulty in expressing emotions, are likely to affect the accessibility to and attentiveness of the schizophrenic parent, and therefore parent-child attachment. Indeed, studies have found poorer interaction from mothers with schizophrenia, and impaired maternal sensitivity and responsiveness towards their infants (Davidsen et al. 2015; Wan et al. 2007). Maternal schizophrenia has been associated with disturbed psychosocial environment and high prevalence of behavioral problems in children (Malhotra et al. 2015), as well as difficulties in the development of autonomy, independence and identity (Vartiovaara et al., 1990).

Beyond the parent-child dyad, family interactions are affected by the patient's symptoms and behavioral inconsistencies. Family System Theory (Bowen, 1913-1990) characterises the family as an emotional unit of interconnected members, who support one another, and each of whom has a role to play and rules to respect. Schizophrenia impacts these roles and rules, with detrimental effects upon family functioning. In the context of schizophrenia, professional and social network support may be crucial for supporting the family as a whole, and in reducing the burden of schizophrenia upon the family unit (Chen & Greenberg, 2004; Magliano et al. 2002).

Literature reveals some evidence for the impact upon children of being raised by schizophrenic parents; however, this complex topic remains under-researched. Most studies have taken a quantitative, reductive approach and have focused on mother-child relationships. Less attention is paid to the wider family or longer-term impacts. Several studies proposed a link between parental mental illness and the risk of children abuse and neglect (Aldridge, 2006; Dunn, 1993). In a previous study about children that grew up with a psychotic mother, the participants reported abuse, isolation and guilt (Dunn, 1993). According to studies with professionals, young carers experience isolation and stigma (Gray et al. 2008). In the UK, young carers have some support from young carers' support groups and the law is changing to preserve their rights. However, in many countries the experience and needs of young carers remain invisible to both public awareness and to their parents. Cooklin (2010) suggests that many parents with mental illness are not aware that their child has become their carer. There is a need for an exploratory qualitative approach, focusing on the accounts of the children themselves, to provide a broader, contextual, understanding of the experiences and their daily, childhood and longer-term perceived impacts.

Method

Design

VN grew up with a mother with schizophrenia, that experience affected her deeply emotionally and she believes that this experience had a high impact in the decisions she made through her life. As a consequence of her own experience, VN was curious to know how this life experience affected other people. For that reason, the purpose of this study is to understand participants' lived experiences of having a schizophrenic parent, and their sense-making of these experiences.

This exploratory interview-based study was guided by principles of interpretative phenomenological analysis (IPA) (Smith et al., 2009).

British Psychological Society (BPS) ethical principles regarding research with human participants were followed, and the study was approved by Sheffield Hallam University Research Ethics Committee.

Recruitment

We recruited participants from a non-profit organization who provide psychological services to relatives of individuals with mental disorders in Valencia, Spain. Adults who grew up with a parent diagnosed with schizophrenia were introduced to the study and invited to participate, excluding those known to have schizophrenia or other serious mental illness. Informed consent was obtained from those expressing an interest, following which interviews were arranged.

Participants

Our six participants (3 men; 3 women) were Spanish. One revealed suffering from moderate depression but, following a careful discussion of risks and rights, wished to participate. Average age was 33 years (range 28 - 37). Two were siblings (a brother and a sister). Five had a mother with schizophrenia; one a father. Parental schizophrenia was diagnosed early in childhood for three participants, and during adolescence for the remainder. One participant was living with their parents, four lived with partners, and none had children. Five had a university degree.

Data Collection

An interview schedule was developed, with questions to explore experiences, and issues relating to perceived impact, wellbeing, beliefs and behaviour. Questions focused on the past, such as:

“What are the key moments that you remember?” and “If somebody asked you to express in a few sentences what it was like growing up with a parent with schizophrenia, what you would say?”. Others focused on the present: “Now that you are an adult, how do you feel when you look back on your past?” “Is it possible to see anything positive about your experience?”; and “How do you think your life would be if your parent had not had schizophrenia?”.

VN (of Spanish origin) conducted all interviews in Spanish. VN's mother has schizophrenia, and she decided to share this fact with participants, but after the interview had concluded. After three interviews, participants' interest and rueful responses ('If I'd known before I would have shared more because I would have known you understood') persuaded her to reveal this fact beforehand with the final three participants. Participants to whom the shared history was revealed beforehand shared more information and appeared more at ease during the interview; however, those interviews proved more difficult to manage. Participants were sometimes as interested in VN's own experience as their own, because of the novelty of talking with someone with that unusual experience. This altered the interviewer-interviewee dynamic somewhat and although this was not a major problem in terms of collecting rich data about participant experience, VN had to redirect the interviews several times, and encourage them to save questions about her own experience until the end of the interview.

Interviews were audio-recorded, lasted around one hour and took place in quiet, private settings, including several in participants' own homes. Recordings were transcribed, anonymized and translated into English for second analysis and dissemination. The translation process was conducted by VN, who is a Spanish native. This process was painstaking and time-consuming. One challenge was avoiding literal translation (word-for-word) in order to maintain the sense or meaning of the original whole. Semantic translation was used, with the objective to convey the

meaning, using words and expression that sounded natural in English. After, interviews were sent to PF, who is an English native for review of linguistic elements.

Data Analysis and Interpretation

Themes were generated according to Smith (2009), through careful listening to audio-recordings and reading of each transcript, data comparisons within and between interviews, through personal reflection by VN, followed by discussion with second author PF. As an academic (PF) and student (VN) of health and social psychology, perspectives from these fields will undoubtedly have been reflected in our interpretation and themes. Additionally VN, data collector and primary analyst, shared some similar experiences with these participants. Data collection and analysis were emotional processes for VN due to her past experience, and sometimes VN found it difficult to reflect upon different meanings that some participants gave to similar painful experiences. Often this was helped by discussing meanings and interpretations with the more objective 'outsider', PF, during thematic work.

Results

Three themes were generated: Role Change and Loss, Prison of Silence, and Who Am I?

Role Change and Loss

This theme reflects the changes in social roles and their home environment as a result of the parent's condition, the loss of their parent to the illness, and the loss of some future goals and roles. It includes the experience of altered interactions within the family and the assuming of new responsibilities. It also describes how participants confronted or adapted to the new situation at home and the perceived changes and losses, both past and present. This theme is made up of four

subthemes: Too soon to become a parent, That stranger that once was my parent, Blaming each other and Avoiding parenthood.

Too soon to become a parent

All of the participants experienced a role change within the family due to the parent's condition, and some, especially females, experienced a lack of freedom. These participants described becoming caregivers at an early age, although the burden was attenuated during childhood among those who had support from an older member of the family.

“You have to be your own mother, and when you can have some authority, in adolescence or as a young adult, you become a mother of your mother.”

The transition from being a child to taking on what were felt as adult or caring responsibilities was traumatic. Participants described their sense of ill-preparedness for and confusion about both the changes in their loved one and the new expectations placed upon them:

“It is very difficult because... it is like a jump in your life, suddenly, you become an adult because at 18 it is so soon... suddenly you are a daughter, a mother of your mother, a mother of your father, of your sister, you don't understand the illness, nobody prepared you, nobody explained it to you [...] suddenly you have a different father, a different family, you are a different person and nobody explained it to you ...”

Some felt unable to take on their new responsibilities. A male participant, feeling unsupported, decided to run away at the age of 18, and took a few years before feeling ready to accept his new role. By contrast, a female participant accepted and took control of the situation, feeling a duty to do so as the oldest daughter; however this decision and the burden associated with her changed

position in family took its toll because, when the situation calmed down, she developed depression that continued to the present time.

“I was in charge of the situation... I was wearing a mask and I tried to take care of everything, and when everything calmed down... then I fell [...] I’m sure that [having a father with schizophrenia] is the reason for all my emotional problems.”

Within this small group, the female participants spoke more than the males of the pressure to become a caregiver and to take care of the family, in keeping with the gendered assumptions around care-taking (Guberman et al. 1992; Eccles, 1987; Moen et al. 1994). However, the women in this study did not accept this role passively, where it seemed to have been imposed upon them. They reacted by creating distance from their families in adulthood, arguably reflecting ongoing resentments regarding these expectations and lack of support. By contrast, those who felt that they had the freedom to make this decision, and did so willingly, appeared to have drawn closer to their schizophrenic parent and were more involved as adults.

That stranger that once was my parent

Participants who were adolescents when their parents developed schizophrenia experienced grief and loss. The interactions and relationship with the parent changed dramatically and very quickly, and participants described feeling confused and emotionally disturbed.

“One day she became a stranger... that deeply affected me... I was talking with a stranger. It was like... like my mother was not there anymore, like she was already dead. That feeling... it was the thing that most affected me emotionally.”

“I remember the first time he came from the hospital, he wore blue pajamas and I saw that he was very weak... like a child, like a sad child... very inoffensive, weak, inoffensive

and delicate [...] like when something is broken. When he was sick, I felt that my body had broken.”

In contrast those participants whose parent had had the illness since they were children lamented that they had never had a real parent and expressed emotional deprivation.

“I needed love, not that she didn’t love me, she loved me in her way, but... that protection, hugs.... I never had that [...] I felt unprotected.”

There was a profound sense of loss within all the interviews, either loss of the familiar, strong parental figure who had been there to love and look after them, or a loss in terms of never having had that love and protection, a sense of its importance and the damage associated with its absence.

Blaming each other

Blame and negative feelings towards both parents were common:

“I know I shouldn’t but sometimes I feel hate... because now I don’t have my father, we had a close relationship and I hate him. I know it is not his fault but I hate him, because he is sick and he left me [...] I also hate my mother because she didn’t help me and she let me take care of things that were not my responsibility.”

In keeping with reactions to grief reported theoretically and empirically (Solomon & Draine, 1996), blaming the parent with the condition for the situation and their loss was often accompanied by feelings of guilt and attempts to compensate. For example, criticisms of the parent during the interview were followed by strong assertions of their love for them.

“I have contradictory feelings, same as when I was a child... she gave me too much freedom, I needed rules [...] I justify her behavior because she is sick and of course I love her [...] I feel a lot of anger inside of me, but I tell you again that I love her very much and all of that but... but... I don't know”.

Participants also blamed their other (non-schizophrenic) parent and often characterised their relationship with them as difficult. Where the mother had schizophrenia, fathers were characterised as harsh and authoritarian, with old-fashioned ideas about gender roles, and as contributing to the mother's ill-health. Sometimes relationships with the other parent improved during adulthood; however, in other cases resentment and blame for their father's poor management of the situation was ongoing. Blame went beyond the child and parent: family members were reported as blaming one other for the parent's condition, with arguments and resentments (for example, between siblings) about who had the bigger burden. One participant experienced self-blame: this woman, who also suffered with depression, blamed herself for the situation, thinking that perhaps she had done something wrong in the past, for which the parent's condition was a punishment. Indeed, the sense of being somehow culpable was not confined to this individual: others also described looking for reasons why this situation had occurred in their lives (*'and not others'*).

Avoiding Parenthood

This subtheme reflects fears about inheriting their parent's condition and passing it onto offspring. Although our participants had (unwillingly) taken on a parenting role in childhood, none had children of their own, a decision which appeared to have been taken actively in most cases:

“I always wanted to become a mother but I am discarding that idea because I am afraid. I know it sounds irrational that my future children will inherit the condition... but people say that your children are the thing that you most love in the world. Well, if my children have to be what I most love in this world, I don't want that for them.”

This loss of future plans and roles, taken for granted by most young adults, was deliberately chosen - a life course they *could* control - as an expression of love. It seemed a sad and stark illustration of the ongoing impact of their childhood experience on the adult lives and futures of these participants.

Prison of Silence

This theme refers to the taboo and stigma surrounding their parent's condition, which was reflected in how participants came to learn about, but then had to maintain, this “secret,” and their resulting loneliness. Four subthemes include: Discovering the secret, Keeping the secret, Mistrust, and I am different, I am alone.

Discovering the secret

Participants recounted different ways of learning about their parent's condition, although the sense of secrecy and search for truth were repeated across interviews. They spoke of their childhood confusion, created by knowing the parent was different, but not why. One participant had searched her house when she was 12 years old trying to find something to explain her parent's behaviour, and on finding evidence of a diagnosis, confronted her grandmother, forcing her family to speak openly about the family secret. Another was unaware of the diagnosis until adulthood. However, in both cases, despite their curiosity and need to know, grandparents refused to discuss the situation, so it remained a taboo topic at home.

“When we were children nobody knew it, then, of course... my grandmother always said that she had depression. I asked her a lot because I didn’t understand anything [...] my father didn’t know anything because they didn’t let him go to the doctor.”

The secrecy was exacerbated by the use of euphemisms. Participants described family members referring to the condition as "depression," in this case, or a “nerve problem” (elsewhere) rather than schizophrenia. Their parent was also described by relatives (especially grandparents) as "too sensitive" or “weak,” rather than as having a mental illness. This could imply a perception that the parent is somehow inferior or at fault for their illness. It could also be a way of protecting the child or protecting the self through denying the illness. The grandparent may also be avoiding terminology which could attract stigma against the family member - and by implication the family as a whole - within a society in which mental illness generally, and schizophrenia perhaps in particular - is misunderstood or unacceptable. Indeed, one commented *"They prefer that he had cancer instead of schizophrenia..."*

Keeping the secret

Not understanding what was happening and then a sense of shame, once they did, plus fear of other others' reactions, left participants alone with their experiences in childhood:

“The thing that most affected me was that I felt different to others and I couldn’t tell it to anybody or at least I felt that I couldn’t do so because obviously at that age... you cannot tell those things, you are eight years old and your friends will not understand it, even I did understand it [...] I never invited friends to my home because I didn’t want them to see my mother.”

Keeping the secret from friends is understandable behavior in children for whom the parent's condition is a taboo at home. As children these participants had learned that the parent and their behaviour were wrong and shameful, making it very difficult for them to reveal this to others, and indeed preventing them from developing the language with which to share their experiences. Despite this, almost all participants broke the taboo and revealed their family secret when they left home. No longer so bound by family rules, they had also developed ways to both understand and explain the situation. Others did not always understand, but sharing the secret gave a sense of release and freedom from the "prison":

"When you are an adult you understand it, you accept it, you talk with people, with friends or with your girlfriend... when I was a child I hid it. [...] Nowadays, I don't hide my mother's mental illness. It is something that makes me feel free."

Nonetheless, awareness of social stigma created a protective approach towards parent and the family, so participants restricted their secret to close friends or a romantic partner:

"I don't want to tell it to anybody because I don't want people to look at my father and my family differently."

Escaping from the prison of silence was particularly difficult when parents and siblings of the person with schizophrenia did not accept the diagnosis. Some participant accounts suggested different forms of ongoing "imprisonment" in adulthood. For example, one participant's mother exhibited persecutory beliefs and, as a result, he felt unable to tell her where he worked but described feeling bad and conflicted about the untruths he was telling her.

Mistrust

Participants' views of and attitudes towards the world and other people were affected by their childhood experiences of a schizophrenic parent, a secretive family, and loneliness. This subtheme is characterised by a sense that others failed to understand them and were untrustworthy.

Participants believed that anyone who had not experienced their situation would be unable understand it. Having lived with profound taboos and social stigma surrounding schizophrenia, and family fears about others' reactions, it is not surprising that low expectations of and a lack of trust in others would extend into adult life. The following extract demonstrates these issues:

“In general, I believe that people are superficial and tend to be cruel. I believe that based on my past experiences and that we never had support or help from anyone. In general, I don't trust people.”

Some described having difficulties in establishing deep connections with other people and others actively preferred to maintain a distance. Difficulties in their parental relationship, such as poor support and arguments, had resulted in a negative view of relationships generally. Having a parent with a mental illness had also challenged or proved unacceptable for new partners.

I am different, I am alone.

Participants reported loneliness during their childhood and adolescence – *“I felt alone, different.”* Feeling alone was commonly reported, but there were differences in the experiences of those who had support within the family from those who did not. The participants with supportive siblings who talked openly about the situation, for example, reported feeling happier and “more normal;” however, having siblings did not necessarily bring support. Some siblings were reportedly unwilling to talk about the parent's condition and give support, and it seemed

that individual coping strategies - such as avoidance or denial - determined these differences.

Those participants who perceived their sibling to be avoidant felt particularly alone and isolated with their thoughts and feelings.

Some participants, especially those without any support, reflected on their need to feel loved:

“I really needed human contact, I was very much in need of love, that... I liked to go to friends’ homes; their parents and siblings were there, I really liked it.”

Some were forbidden from going to friends’ houses, which aggravated the feelings of loneliness, and one participant attributed her adulthood insecurities and introversion to her isolation in childhood. Isolation went beyond individuals to affect the entire family. Due to their fears that the person with schizophrenia might say “weird things,” causing shame and embarrassment, one participant reported how her family avoided social activities with other families or relatives.

Some participants complained about the lack of external support, for example at school or from doctors. Two participants described their doctor as cold and insensitive to the family, observing that doctors seem to be “afraid of them” and maintained an emotional distance. Some reflected on how important it was to be able to normalize by talking openly without feeling judged.

Insensitive and avoidant treatment by professionals meant that opportunities for support from important agencies outside the family were lost.

Who Am I?

In addition to mistrust of others, some of our participants struggled to trust and accept themselves. They were concerned about who they were now and who they were becoming. This theme reflects the ongoing impact of their childhood experiences on participants' perceived

identity, self-esteem, stability and success in relationships. Subthemes are Insecurities, I Am My Parent's Child, and Finding Meaning: Finding Me.

Insecurities

When talking about themselves and their feelings, there were differences between men and women in openness, which is in keeping with previous studies of sensitive personal topics (Petrides & Furnham, 2000); however the gender of the interviewer (female) may also have been a factor in explaining differences between men and women in interviewee openness and self-expression (Sultan & Chaudry, 2008).

Women generally spoke about themselves in more depth, and these participants reflected on difficulties in attaining a positive sense of self and identity. The participant with depression expressed feeling different and “lost”; another described herself as introverted and insecure. Her heavy childhood burden had made her now desirous of freedom, but also unable to accept new responsibilities through a fear of failure. A third believed that her mother, her experiences and her responsibilities had helped shape her current self, in positive and negative ways:

“I’m mature, I’m responsible, I am too responsible [...] I’m strong but at the same time I’m weak. Because of everything I have experienced, I have a lack of confidence in myself, that self-confidence that makes you feel sure of yourself when you have to make a decision.”

Some expressed concerns about 'normality' of their own thought processes, based on fears of developing schizophrenia themselves. Anxiety about and self-analysis of thoughts and behaviors to check whether they might reflect the onset of schizophrenia were common in our sample.

“I am very worried if I might develop it [...] It worries me and I analyze all my thoughts, sometimes I question my own thoughts ... If I am interacting with other people in a normal way. It can be inherited so I may have that illness...”

I Am My Parent's Child

Some believed that emotional instability - through the damage sustained in childhood - had made it impossible for them to have a healthy relationship. One described having “*failed*” to do so many times because she was selfish, emotionally unstable and had frequent and sudden mood changes. She believed that being with her was “*an adventure*” but also very difficult and described coming to a realisation that being with her must be like being with her mother.

Although male participants reported having a difficult relationship with their fathers because they thought they were too authoritarian and insensitive with their mothers, yet the same participants reported feeling more attracted to “sensitive” girls.

“I’ve always felt attraction for sensitive and insecure girls... and they are usually attracted to me... I compare them with my mother that I can’t do anything because she is ill [...] I inherit from my father that I am... authoritarian, is not that I am very authoritarian but sometimes I am a little harsh. I think this is normal because it is what I saw when I was a child, but I try not to be like that, but sometimes I am.”

This participant seemed to see the same unhealthy patterns of behaviour that he witnessed in his parents as a child, but felt incapable of changing this. The same participant reported using drugs in adolescence, aggressive behavior and difficulty in expressing his feelings in relationships.

Finding Meaning: Finding Me

Participants tried to find meaning in their experiences, in their past decisions, in who they were today and in thinking about their future. There was some sense of positivity within the data, but it was not clear to what extent this reflected a reinterpretation of what had happened, nor the extent to which positive reinterpretations actually alleviated the distress in any real sense for most of our participants.

“you feel misunderstood [...] mature too soon [...] see the dark side of life too soon”

This brief summary of the experience of having a parent with schizophrenia expresses some of its difficulties and negative impacts; however, five of the six participants reported some positive and uplifting experiences, despite the problems. For example, they described becoming better people, having more empathy and sensitivity, and some were proud of how they had managed the situation.

“The fear, the loneliness, the unpredictability.... I translated them into responsibility, in resolution, and they made me a stronger person.”

On the other hand, these accounts sometimes appeared to reflect the need to find and express at least something positive and meaningful within an otherwise bad experience, rather than a truly positive part of that experience. It seemed that some were using positive reinterpretation as a coping strategy when reflecting on what had been a dark and difficult situation, in order to identify some meaning and purpose for themselves within it. In keeping with this perspective, one of the participants stated that, although he learned how to be a father and to be stronger, he couldn't see this as a positive, and he would have much rather not have lived through his experiences.

When reflecting on positives, most could not identify anything beyond the sense that “it could have been worse.” Those who hypothesized about an alternative reality reported that they

probably would be happier and less insecure about themselves, and they would have had a better relationship inside their family without blaming each other.

Participants described experiencing a profound life change when they left their parents' home because they had distance and had space and time to gain insight into themselves. Although some described being constrained by caring duties, leaving home had allowed them to progress with previously disrupted life goals, such as resuming previously disrupted University studies. Leaving home had led to a search for self and a future direction in life for most:

“It is an experience that has disorganized my life, and it has taken me a long time to put all the pieces together and figure out who I am and how I want to live.”

As expressed here, the search for self and direction had proved challenging. Participants spoke about needing a long time to find their path because they didn't have a guide, and some were still looking for it. One woman described finding peace through the realisation that her mother's behaviour was due to her illness, and that she was not like her mother. Thus part of finding themselves and their own way meant understanding the past. She observed:

“You need to separate all the pieces and organize them, because without equilibrium you cannot find peace. And when finally, you separate everything and you classify it and starts to organize it... then you start to find who you are.”

People are driven to make sense of themselves and their lives, and this is generally achieved through creating narratives (Baumeister & Newman, 1994). Meaning making is particularly challenging and important in difficult life circumstances (Riessman, 2001), and making sense of disorder and distress is a vital part of a positive coping process (Park, 2013). For our participants, stigma, secrecy and silence prevented the development and articulation of life narratives, and it

appeared that they had only been able to begin the important tasks of creating their stories, seeing meaning in their experiences and finding themselves once out of the restrictive family environment.

Discussion

This study provided insights into the impact of growing up with a parent with schizophrenia. We consider that VN's experience was an advantage to understand and reflect the feelings of the participants, but even more important, the participants that knew VN's experience were more open and trustful to disclose their experiences and feelings. Participants reported that it was easier to open up to someone who could understand and not judge them. Although this was at some degree expected, we were surprised by the extent to which participants were affected by knowing that information. Findings from analysis of the six interviews suggested that social stigma and taboos surrounding mental illness and family reluctance to discuss the parents' condition created a "prison" of silence, secrecy and loneliness for participants. Indeed, this was reflected in the process as well as the outcomes of the research, as participants that didn't know about VN's experience were more reluctant and "careful" to talk about their experience. The impact of schizophrenia upon the affected parent forced the child to grow up quickly, take on a caring role, and damaged the quality of both the parent-child relationship and other relationships within the family. The disease also created fears within each participant about the normality of their own thoughts and behaviours, given the possible heritability of schizophrenic traits (Chou et al. 2016), and none had yet "risked" passing on the genes by having children of their own. The sense of being alone within the family and through avoiding having children, was compounded by difficulties in trusting others and in forming, sharing and behaving appropriately within romantic relationships. Some sought to see the meaning and positive implications of their

experiences, such as being stronger as a result; however most perceived their journey to date as dark and difficult, and few were clear and confident about their future.

Our findings about the stigma and silence surrounding schizophrenia are in keeping with previous work (Gonzalez-Torres et al. 2007; Lefley, 1989; Wahl & Harman, 1989; Corrigan et al. 2006). Families were unwilling to talk openly about the parent's schizophrenia, and the older generation in particular used euphemisms or more acceptable alternatives (e.g. "depression" or a "nerve problem"). However, some studies reported the benefit of talking and discussing openly with the children the parent's mental illness (Falcov, 2004) and the benefit in understanding what is really happening to their parent, so they don't feel responsible (Cooklin, 2010). According to Angermeyer et al. 1996 and Jorm et al. 1997 society tends to view mental illness as the result of the person being "too sensitive" or "weak." This contributes towards stigma because the individual is constructed as blameworthy for not being "strong enough," which also makes their condition shameful for other family members. More recently, Jorm et al. (2005) reported that beliefs linking "weakness of character" with schizophrenia were decreasing, and being replaced by its attribution to childhood problems. While reducing individual responsibility, families retain responsibility under this explanation, and may still therefore respond with shame and silence. Our findings suggested that families typically struggled to accept the condition and would have preferred a physical illness like cancer. Strong stigma within the family may prevent relatives from seeking professional and social support, making the experience an isolating one for all. According to Lakey (2000), the quality and quantity of our social relationships influence health and wellbeing. Participants of this study reported a lack of social support both within and beyond the family unit, which they believed had impacted them very negatively, in terms of loneliness, burden and stress.

Our participants shared accounts of how interactions within their families had shifted in the presence of schizophrenia, especially their own experiences of becoming carers for their parents. This is supported by Family Systems Theory (Bowen, 1913-1990), which describes how the interconnectedness between individuals in the family mean that anything happening to one member has an impact on everyone in the family. One impact can be that, in the case of health or well-being changes, other family members have to take on new roles to meet the gaps left by the unwell person (Lefley, 1989), such as a grandparent or child taking on the parental responsibilities. Our findings suggested that female participants in particular perceived an expectation that they would accept a caregiver role, especially where they were the oldest daughter, often against their will. It was not only our participants whose roles had changed: other family members argued with one another about individual shares of the burden. As in other studies (Corrigan et al. 2006), blame, resentment and guilt were common and influenced interactions within these families.

Participants in the study spoke about failing to create an emotional bond with their parents and how this had affected them throughout their lives, in both their personal traits and their interpersonal skills and relationships. Our findings are in keeping with the principles of attachment theory and with studies which have reported difficulties for schizophrenic parents in expressing emotions (Tandom et al. 2013), a symptom which is likely to make a schizophrenic parent less accessible and attentive to their child's needs. Our participants described losses of this type in this important relationship. We found similarities to Davidsen (2015)'s results, in which some participants reported a lack of maternal sensitivity and responsiveness. One of our participants, for example, reflected on her need to feel loved and for human contact, several felt their parents were not emotionally available to them, and all related a sense of insecurity in many

aspects of their lives. These issues affected both those whose parent had schizophrenia from their young childhood and those where the condition occurred later, in or beyond adolescence. While Bowlby (1907-1990) studied emotional bonds between a child and a caregiver, and Hazan and Shaver (1987) that between adult romantic partners, this study also suggests that a disruption in emotional bond between a young adult and their parent can create grief and loss, and may affect their adult relationships.

The experience of growing up with a parent with schizophrenia altered these participants' perceptions of and behavior in adult relationships. Other people were viewed as mean and superficial, or considered unable to understand or accept their situation. Reported trust and intimacy problems made it difficult for them to form secure adult relationships, in keeping with Duncan & Browning (2009). These were exacerbated, according to participants by their own unstable, unhealthy or dominating behaviour when in relationships, which they generally attributed to their similarities to their parents.

Limitations and Implications for the Future

Among the methodological limitations of this study, it is important to mention that this study does not pretend to be representative. Five of the six participants had university degrees and all participants went to a non-profit organization for relatives of people with mental disorders searching support, thus participants are likely to represent a well-educated, assertive and support-seeking group of individuals, compared to the broader population. However, this qualitative study has helped generate insights into the subjective experiences and perceived impacts among adults who were raised by a parent with schizophrenia, a little researched area. The findings from this in-depth inductive study with this small, unrepresentative study could be extended through

similar research with other populations, or alternatively tested in a larger sample using a more deductive approach.

Another limitation was linguistic, in that interviews were conducted by VN, whose first language is Spanish, and then translated by the same person into English for analysis by both authors. Fluency in both languages facilitated the appropriate translation of idioms which do not translate directly; however, it also introduced some potential for unconscious bias in how the Spanish was interpreted, even before the interpretive process of analysis began. Although considerable efforts were taken to closely and accurately reflect the participant accounts at this stage, it would have been ideal had two bilingual authors translated the interviews, compared and agreed a final version before analysis.

Importantly VN, like the participants, grew up with a schizophrenic parent. Indeed, it was her experiences which drove an initial interest in this topic, and her desire to compare her experience with other people. It is likely that her experiences were reflected in her interpretation; however, both authors were involved in analysis, meaning that VN's individual perceptions as an “insider” were set alongside PF's, who takes a more “outsider” position in relation to the topic. One interesting dilemma related to this point was the decision about whether and when to reveal VN's shared experience to our participants. In the spirit of informing and not deceiving participants, the initial decision was to reveal this fact; however, we wished to avoid the interview being focused too much on her own experience, so at this stage of data collection, the information was provided after the interview, which still gave participants time to add or withdraw data if they wished. The positive responses to this led us to reveal the fact before interviews for the final three interviews. These decisions affected to a small extent the quality of the data which were shared. Participants who learned of the shared experience before the interview were more open

in talking about and showing their emotions. Those informed after the interview lamented that, had they known, they would have expressed themselves more freely. Reflecting on these comments in the light of the dataset, it seemed that participants felt more comfortable because of their beliefs that only others with similar experiences could understand them, would listen without judging, hence felt more comfortable to disclose their experience (Rogers, 1975).

Finally, our participants reported that they had found the interviews therapeutic. The invitation to narrate past and present experiences using qualitative interviewing methods can be therapeutic because it allowed the participants to revisit and reorder their past experiences (Birch & Miller, 2000). The participants had the opportunity to talk openly and freely about things many had kept hidden, and it has been found that talking about their problems is an effective coping strategy for caregivers (Steele & Fitch, 1996).

Mental health workers, especially psychiatrists and psychologists, should be aware of the risk of depression, loneliness, caregiver burden, negative thoughts and the need of support within this population. Winefield and Harvey (1994) found that some family caregivers desired but lacked reward and recognition for their caring work. According to Winefield (et al. 1998) family caregivers need professional support and respect from mental health professionals. In keeping with our findings, and the evidence of stigma and insufficient support, it may be that support groups would offer a valuable outlet where caregivers could talk about their experiences with others in a similar situation. Some previous studies have reported benefits for this group such as reduced level of burden and depression (Chien & Norman, 2009; Chou et al. 2002) and an improvement in family functioning (Chien et al. 2004).

Future research directions might include similar qualitative research with people from different cultures to compare their experiences and consider how culture impacts their experiences, given

the importance to our participants' experience of stigma and secrecy. Also, since it became clear that loneliness and isolation are real issues for this group, it would be beneficial to explore the effectiveness and impact on wellbeing, identity and relationship success of support groups for people that grew up with a parent with a psychotic disorder such schizophrenia. Finally, these six accounts suggested that relationships between partners where one has schizophrenia are characterised by neediness and sensitivity in the sufferer and coldness / insensitivity in the partner and the implication that coldness and authoritarian behaviour within couples. This interesting insight could drive research into partner selection in this context.

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