

A narrative analysis investigating the impact of first episode psychosis on siblings' identity

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Abstract

Research investigating the impact and experience of first episode psychosis amongst siblings is limited. This study reports the findings of a narrative analysis of the accounts of four siblings, two male and two female, aged between 17 and 24 years, of young people with a first episode of psychosis. The aim of the analysis was to explore the impact of this experience on siblings' sense of self and their identity development and the roles they adopt within their families. The analysis focussed on the core narrative, tone and genre of each account as well as providing a cross-case analysis. This cross-case analysis indicated an overarching genre of 'rite of passage' within which a gender difference was interpreted. The emphasis in the accounts of the two young women was on finding personal meaning whereas, for the two young men, the emphasis was on taking up responsibilities. As found in other studies of serious mental health problems, siblings provide much direct and indirect care for their families. The implications for services providing support to siblings and families in early intervention services are discussed.

Introduction

Research exploring the experiences of siblings of those with a diagnosis of psychosis or serious mental health problems is limited relative to research focussing on the experiences of parents. Even less attention has been paid to siblings' experiences at the onset of psychosis and their experience of change during this period. In the only published study to date, Sin, Moone and Harris (2008) conducted interviews to understand the experiences and needs of ten siblings of individuals with first episode psychosis. A number of key issues were highlighted such as siblings feeling overwhelmed by the psychological impact of their brother's or sister's onset of psychosis and by the impact of it on their own lives and emotional wellbeing; their concerns for others, particularly younger siblings, their parents, and their own relationship with their affected sibling; and, their roles and coping patterns, for example, supporting their parents as primary care-givers and encouraging and supporting social activities and engagements. This latter finding is similar to previous research highlighting the support that siblings offer their parents as secondary caregivers in engaging their brother or sister in normalising activities (Birchwood, 2003). In common with research investigating siblings of people with serious mental health problems, Sin et al. (2008) discovered that siblings were also able to identify positive gains from their experiences of having a brother or sister with first episode psychosis. Positive gains included enhancement of personal development, developing close sibling bonds, and greater resilience within the family.

The onset of psychosis is most likely to occur during a critical period in a person's development. During this time in life, a person would usually be increasing their independence, moving away from their family and, according to Erikson (1968), is the time in life when identity development is central. The onset of psychosis is therefore likely to significantly affect and possibly disrupt these natural processes in an individual's life. Indeed, Wisdom, Bruce, Saedi, Weis and Green (2008) found that the onset of mental illness was associated with a loss of self or previously held identity, which needed to be overcome, or at the very least managed, to obtain hope for recovery. The onset of psychosis in an individual is also likely to occur during a

critical period in a sibling's development (late adolescence to early adulthood) and therefore may also impact the course of the sibling's development. Indeed, research by Lukens, Thorning and Lohrer (2004) indicates how the cumulative impact of a brother's or sister's serious mental health problems appeared to impact on a sibling's evolving sense of self and thoughts about the future. Given that, as noted above, siblings comprise an important part of the family care system and will likely have their own specific needs, this study set out to explore the impact of first episode psychosis on young adult siblings' sense of self and the roles they adopt in an evolving family system that is responding to an initial onset of psychosis.

Method

A narrative methodology was employed. McAdams (1985) argues that narrative is at the core of self-definition, and further, that identity is a life story. Murray (2003) defines a narrative as "*an organised interpretation of a sequence of events*" (p.113) the primary function of which is to bring order to disorder and give it meaning. Social scientists have therefore used the study of narrative to explore the ways in which people make sense of, and adjust to, the disruption of illness or disability.

Participants

The research took place within an Early Intervention Service (EIS) in London. Siblings of clients on the EIS caseload were eligible to take part if they were between 16 and 25 years old, were living with or actively involved in their sibling's life at time of onset of psychosis, and had the ability to provide consent. Participants were excluded if they had a recognised diagnosis of mental illness or learning disability. During the recruitment phase of the study, the EIS caseload totalled 72 clients. Of these, ten clients had a sibling meeting the study eligibility criteria. All ten siblings were invited to participate. Of these, 6 agreed to be contacted of which five agreed to participate. Of these five, one person did not attend a scheduled interview on two occasions. Consequently, four people participated (see Table 1).

Insert Table 1 about here

Procedure

The study was given a favourable opinion by a National Health Service Research Ethics Committee. Participants received information sheets before the study and written consent was obtained prior to conducting each interview. A semi-structured interview was conducted with each participant. This included prompt questions asking the participant about their life before their brother or sister became unwell, their life when they first learnt that their brother or sister was unwell, their life at the current time, their relationship with their sibling, other family members and peers, and in what ways, if any, their sense of who they are and what life is about had changed. Interviews lasted for approximately one hour and took place within a community hospital. All interviews were audio-recorded and transcribed verbatim.

Data Analysis

There is no definitive way in which to conduct a narrative analysis and approaches vary depending on the investigator and the research aims (Riessman, 2008). In this study, the analysis comprised four stages, each informed by a number of narrative methodologists. The first phase of the analysis involved repeated reading of the transcripts in order to become familiar with structure and content. The second phase drew upon the descriptive phase of Murray's (2003) constructivist approach. Briefly, this involves writing a short summary of each narrative in order to identify and illustrate key features as well as gain a sense of the underlying orientation, form or genre of the narrative. The third phase drew on methods employed by Thornhill, Clare and May (2004) in a study of the narratives of recovery from psychosis. This involved focussing on narrative genre (e.g. plot development), core narrative (e.g. the main theme) and tone (the manner in which the story is told) in each account. The fourth phase involved conducting a cross-case analysis in order to draw out similarities and differences between narratives. Three researchers were involved in reading and re-reading the narratives and discussing and developing each phase of the emerging analysis.

Findings

Below, a very brief summary of each participant's context is given in order to provide the reader with some orientation to the participants' narratives. This is combined with a brief summary of the individual analyses of core narrative, tone, and genre. Following this, the cross-case analysis is presented which focuses on commonalities and differences, in particular related to genre across the narrative accounts.

Case Study Analysis of Core Narrative, Tone, and Genre

Table 2 gives an overview of core narrative, tone and genre of each participant's account. Following this, a description of these main narrative features is given with a brief account of the context of each participant's story.

Insert Table 2 about here

Luke is a seventeen year old white British male. He has an older brother and a younger sister and was living at home with his parents and younger sister at the time of the interview. Approximately one year previously Luke's brother had experienced a first episode of psychosis while he was travelling abroad and Luke and his father brought him home. The core narrative identified in Luke's story was "*I had to put it all on hold*". This narrative was frequently present in Luke's story as he often referred to time being taken from his own life in order to look after his brother. The most significant tones identified within Luke's narrative were: 'shock', for example, at the onset of his brother's psychosis, 'pragmatism' as illustrated by his active, practical response to the situation, and, 'ambivalence' as revealed by a tension between wanting his own life to progress whilst wanting to support his brother. The overall genre of Luke's story appeared to be one of a 'dutiful brother'. His apparent self-less role towards his brother was prevalent throughout in that his duty appeared to override his own hopes and aspirations.

Nick is a recently married twenty-four year old white British male. He has a younger sister, aged nearly twenty-one, who had experienced a first episode of psychosis approximately three years ago. At this time, Nick was in his final year at university and lived away from home. Nick's parents did not tell him immediately due to protecting his studies. The core narrative identified in Nick's story was "*one*

step removed". Nick often used these words to explain the role that he took in his family when his sister became unwell. Nick's perspective of being one step removed seemed integral to his role/identity within his family both in a physical and emotional sense, and this appeared to help Nick to cope and to support his family. The key tones identified throughout Nick's story were: 'inquisitive' which was evident through his research into psychosis and his enquiring stance during the interview, 'pragmatic' which was evidenced in Nick's narrative with regard to his non-emotional, doing-orientation, and, 'reflective' as illustrated by his contemplative nature throughout the interview. Nick's story seemed to be that of a 'stoic quest' to find the appropriate facts to help his family and himself cope and respond to his sister's psychosis.

Sarah is a twenty year old white British female. She is the middle child with two brothers, the older brother being one year older than her. Sarah's older brother had been given a diagnosis of depression approximately four years ago. Around two and half years ago, just before she started university, Sarah's brother experienced a first episode of psychosis. At this time, Sarah lived at home with her mother, father and both of her brothers and was studying for her A-levels, including one in psychology. Sarah was not particularly close to her family prior to her brother's first episode. The core narrative identified in Sarah's story was (I, they) "*don't really kind of understand*". Sarah uses these words to describe her initial response to her brother becoming mentally unwell and further refers to herself, her family, and others 'not understanding' throughout her story. Towards the end of her story, Sarah explains how frustrated she is with other people for not understanding about mental illness and this drives her ambition to influence people's opinions in her future career. The key tones identified in Sarah's story included: 'shock', portrayed both by what she said about her response to her brother's first episode and also the initially very disjointed nature of her narrative, 'empathy' which seemed to be towards her brother and others with mental illness, and, 'passionate' which appeared to be especially related to bringing about change through her future career aspirations. The genre that appeared to summarise the type of story that Sarah told was 'survivor to reformer', reflecting how she overcame the initial shock and distress with the hope of contributing to the reformation of others through her career in psychology.

Hannah is a twenty-two year old white British female. Hannah has an older sister aged twenty-three years. Hannah grew up with her sister and mother. Hannah and her sister left home to go to university at the same time because Hannah's sister deferred a year. While they went to different universities they remained in contact. During her second year at university, one of Hannah's friends appeared to become mentally unwell and, in the same year, died. The following year, Hannah recognised similar behaviour or 'symptoms' in her sister and spoke to her mother about it. The core narrative identified in Hannah's story was "*everything happens for a reason*". Hannah used this phrase to describe her outlook on life and the way in which she has made sense of both her sister's illness and the previous illness and death of a close friend and was evident throughout her story. The key tones identified in Hannah's narrative include: 'ambivalence', which seemed apparent in Hannah's indecision about whether she wished to know more about her sister's illness, 'accepting' in that her philosophy towards life events seemed fatalistic, and, 'passionate' in that she seemed committed to living life to the full and finding meaning, suggesting that others should do this regardless of their problems. The overall genre of Hannah's story was identified as 'out of darkness'. The 'darkness' that Hannah appeared to emerge from was the experience of seeing her friend become ill and then die, which caused Hannah to question life.

Cross-case Analysis

While unique in their individual genres, there appeared to be a number of similarities between the narratives, for example in terms of the shock of the first episode, taking a pragmatic response and feelings of ambivalence. Further analysis indicated differences in genres based on gender. In conceptualising this, it is possible to conceive that all narratives have an overarching 'rite of passage' genre, perhaps to be expected in accounts of adolescent identity development/change. However, it does appear that the passage for men and women in this study was somewhat different.

Male Narratives: 'Call to Manhood'

The genre 'call to manhood' represents an interpretation that both Luke's and Nick's narrative accounts demonstrated roles of responsibility in relation to their families, which is also evident in the 'pragmatic' tone of the stories. While similar in

genre, the process of the 'call' was different in each narrative. For Luke, the younger brother, the 'call' appeared to be a shock, and for Nick, the older brother, the 'call' appeared to be a continuation of a life stage transition that he had already commenced. This was evident through Nick's age and his circumstances, as he was leaving university and preparing to start employment at the time of his sister's illness. When describing their response to their sibling's first episode of psychosis, which in each case appeared to include taking on responsibilities within the family, both Luke and Nick described themselves as doing what they had to do, as though they were 'stepping up to the mark':

"I always had to find out how I could deal with it next" (Luke)

"...there was a completely defined role that I needed to take on and therefore, naturally I took that role because that was sort of what was required..." (Nick)

Doing what had to be done in the family seemingly went alongside a change in both Luke's and Nick's roles in relation to their sibling with psychosis. For example, Luke's birth order role as the younger brother shifted to a temporary older brother role while his brother was ill:

"...you've got to worry about what he's doing, and whether that could end up going bad or not".

Nick's role as the older brother seemed to become enhanced:

"... I'm much more ready to check to make sure she's ok and to actually be a support to her..."

Perhaps more significantly, both Luke's and Nick's roles appeared to change through increased responsibility in relation to their parents. They both appeared to have developed relationships with their parents that involved more mutual respect:

"I think I have proved to them that I'm able to kind of deal with more difficult situations" (Luke)

"...my parents and I are definitely in a, in a sort of a two-way thing...what we do is sort of speak to each other for advice and our opinions on things, and so I think at the

time that my sister became ill I was old enough to, for them to consider me as another adult who they could speak to... ” (Nick).

Nick’s role change also appeared to include trying to provide himself and his parents with information about issues related to his sister’s illness:

“...I don’t know whether it’s a generation thing but it comes less naturally to my parents, they’re more happy to accept whatever care is given as the appropriate care rather than to learn or at least learn or work out exactly why certain drugs are being given or why...”

With the increased responsibility, and changing family roles, both Luke and Nick seemed to recognise they had more resources and abilities. In particular, this could be seen in Luke’s narrative as an early call to manhood, as he had not previously appeared to have begun this transition:

“...the main thing that 6 months had done is it’s made me grow up and stuff because I’ve been given a lot of responsibilities to do, I’ve had to look after my brother, so it’s changed me in the way I think of things...”

In Nick’s narrative, this recognition could be seen as an appropriate transition to manhood. As he was finishing university at the time his sister became unwell, he had already developed competency and skills in enquiry and saw it as his natural role to pass on his findings to his parents:

“I think I’m probably more ready to investigate those things, to question those things and then discuss them with my parents. And then also, I think also, tied to that, my parents probably just aren’t just aware of what information’s out there...”

Female Narratives: ‘Phoenix Rising’

The genre ‘phoenix rising’ represents the interpretation that both Sarah’s and Hannah’s narrative accounts demonstrate a journey through very difficult and distressing life events, which they attempt to make sense of, and from which they both emerge as they find personal meaning. Sarah’s and Hannah’s accounts also had some similarities in tone, both expressing passion in finding personal meaning. While similar in genre, Sarah’s and Hannah’s journeys appear to commence at different

points. For example, Sarah's shock, distress and confusion appeared to relate to her brother's onset of psychosis, whereas Hannah seemed to have begun this phase of her journey prior to her sister's onset of psychosis, when a close friend who also appeared to have a mental illness died the year before:

"...it was just so like distressing because it was so just like different to normal and what he's normally like" (Sarah)

"I'm thinking back to when, my friend as well, and I'm trying to relate it back because he had a really bad experience of like, thought he was like a messiah, and he was like, it's devastating to listen to one of your best friends and stuff, but with [sister], I know it's not as bad but I kind of related it to the two, just extreme thinking and extreme behaviour..." (Hannah).

Sarah and Hannah attempted to make sense of these experiences. Sarah's prior knowledge of psychology and attempts to make sense of her brother's illness went alongside her changing role in the family, in particular in relation to her parents:

"I think also because I do study psychology in particular...because they don't know really anything about it, I kind of at one point knew more than they did sort of thing...so I definitely got closer to my parents because we'd speak about it and kind of try and get more points of view and like, like ideas on how to help him..."

Hannah's role or status also appeared to change in relation to her sister and mother:

"...you can't really mess around with her [referring to sister] as much, she takes things like to heart a little bit more than she usually would and mum fusses over her a little bit more than she used to...and when she's there it's more about her than it is about me, but it doesn't really bother me, I don't really need my mum's attention at the age of twenty-two, it's just, it's different, it can be different..."

A sense of frustration with others was common to both Sarah's and Hannah's narratives. For example, once Sarah had accepted and adapted to her brother becoming ill, she became frustrated and angry with people who she considered to be ignorant to mental health issues:

“...I think quite a few people just have this very sort of, very un-understanding attitude which really frustrated me, really frustrated me at the time and I remember getting into quite a few, like, very angry at quite, at a couple of people like who would come out with some things that I didn’t, that I didn’t like to hear...”

Hannah’s frustration appeared to have arisen because of a change in the way in which she viewed life given her experiences. Hannah found it very frustrating that her sister had a different outlook on life:

“...I think that ever since that happened I think ‘you’re still alive, you’re still here, you can do whatever you want with your life...and I think that’s why I’m unsympathetic towards it, cause I’m like ‘come on, you’ve got the rest of your life to make what you wanna be, if you wanna do it you’ll do it’, so maybe that’s what happened and that’s why I’ve been like that...”

Hannah also found it frustrating that her mother seemed to support and encourage her sister’s way of coping:

“...I think in that sense I like kind of sometimes got a bit frustrated with her that she [referring to sister] was sitting and moping around and mum was fussing around her like she was a four year old or something...”

Having experienced and made sense of these distressing life events, at the time of the interviews both Sarah and Hannah’s narrative accounts appeared to suggest that they were rising from their despair with new personal meaning. Sarah showed a desire to become actively involved in spreading the message to others and seeing how she could potentially use her career to make a difference:

“...it’s kind of like made me very sort of like, personal experience, it’s made me wanna help people really with it and help the whole, like put more, like get more research for it I guess.”

Hannah’s attempt to find meaning in both her friend’s illness and death and her sister’s psychosis seemed linked to a change in outlook regarding the role of fate:

“I think everything happens for a reason, and I became more aware of (sister) and maybe me and mum...got her help in time because I'd already experienced it with someone else, there's just kind of interlinks and stuff like that.”

Discussion

The rites of passage identified in the current study, which seemed to develop the participants' sense of identity, and which all participants appeared to frame in a progressive way, support previous studies that have found siblings experience positive gains from their brother's or sister's mental health problems (Sin et al., 2008). However, rites of passage include the experience of loss and distress, as well as progression and growth. Rites of passage are examples of role replacement which can bring jeopardy, for example through relinquishing rewards associated with a previous role (Quinn, Newfield, & Protinsky, 1985). As with previous studies that have investigated the impact of mental health problems on family members (Lukens et al., 2004), themes of loss and burden emerged in the current study. However, when integrated into the whole story, rather than fragmented and investigated out of context, loss and burden might be perceived as less problematic, and more symptomatic of transition. Empirical studies support the idea that positive change occurs following trauma or adversity. Some of the positive outcomes identified include enhancement of relationships and change of self-perception and life philosophy (Higginson & Mansell, 2008). Positive changes following adversity have been referred to as post-traumatic growth, stress-related growth, perceived benefit and thriving, and are collectively known as adversarial growth (Linley & Joseph, 2006). The present study interpreted different emphases in stories based on gender. For the young women the emphasis seemed most related to the development of personal meaning whereas, for the young men, the emphasis was on adopting responsibilities and was characterised by pragmatism. The findings, or their interpretation, could be related to ideas about gender-appropriate discourses in society.

Implications

At some stage in their experience, all participants needed to investigate issues related to mental health to aid their and their families' understanding. These findings add to the current literature which suggests that well-siblings of individuals with

serious mental health problems desire information (Friedrich, Lively, & Rubenstein, 2008). Importantly, all participants played a role in the care-giving and recovery of their sibling. This occurred both directly and indirectly, through support and advice offered to parents. This supports Birchwood's (2003) findings regarding the perceived value of siblings in engaging their brother/sister in recovery and normalising activities. These findings further emphasise the potential benefit of services providing resources to meet the needs of siblings. It might also be beneficial if services were to highlight to families the demands that siblings could face and the supportive roles they may adopt, providing information specifically with regards to this aspect of siblings' involvement. In relation to this, and specifically linking in with the findings of this study, White and Epston (1990) have argued that interpreting and relating crises based on rites of passage analogy enables the crisis to be constructed in terms of progress, rather than regression, without denying distress. A narrative approach to therapeutic work within Early Intervention with siblings and other family members might therefore be recommended.

Limitations

This study involved a small number of participants all with similar socio-demographic backgrounds. The aim of narrative research is not to produce findings that might generalise to populations. Nevertheless, to develop the theoretical and practical implications of this study, replication and extension is necessary. Future research might involve siblings from different backgrounds and cultures in order to increase understanding about the impact of culture and society on one's meaning making processes, and thereby increase the cultural applicability of theory and services. This would add to recent research which has explored the treatment experiences of care-givers of Pakistani origin within the context of Early Intervention for psychosis (Penny, Newton, & Larkin, 2009). Participants in this study may represent those who have grown as a result of their experiences. However, while volunteers may have progressive stories with 'happy endings' to tell, a holistic approach to data analysis can inform of the nature and context of potential difficulties of those siblings who do not volunteer to share their stories in this way.

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Table 1: Participant characteristics

Pseudonym	Age	Gender	Ethnic Group	Duration since onset of sibling's psychosis	Education
'Luke'	17	Male	White British	1 Year	Up to 18 Years
'Nick'	24	Male	White British	3 Years	18 + Years
'Sarah'	20	Female	White British	2.5 Years	18+ Years
'Hannah'	22	Female	White British	1 Year	18 + Years

Table 2: Results of analysis of core narrative, tone, and narrative genre

	Core Narrative	Tone	Genre/Form
Luke	<i>"I had to put it all on hold"</i>	shock, pragmatic, ambivalent	dutiful brother
Nick	<i>"one step removed"</i>	inquiring, pragmatic, reflective	stoic quest
Sarah	<i>(I, they) "don't really kind of understand"</i>	shock, empathic, passionate	survivor to reformer
Hannah	<i>"Everything happens for a reason" (?)</i>	accepting, ambivalent, passionate	out of darkness