Parry, Sarah and Varese, Filippo (2021) "Listen to the parents... Really listen to the child!" Family narratives of supporting children hearing voices. Psychosis: Psychological, Social and Integrative Approaches, 13 (3). pp. 209-219. ISSN 1752-2439

DOI: https://doi.org/10.1080/17522439.2020.1856174

Publisher: Taylor & Francis (Routledge)

Version: Accepted Version

Additional Information: This is an Accepted Manuscript of an article published by Taylor & Francis in Psychosis: Psychological, Social and Integrative Approaches on 1st February 2021, available at: http://www.tandfonline.com/10.1080/17522439.2020.1856174

Title: “Listen to the parents… Really listen to the child!” Family Narratives of Supporting Children Hearing Voices

Short title: *Narratives of Supporting Children Who Hear Voices*

Dr Sarah Parry*[1], Dr Filippo Varese[2]

1Dr Sarah Parry, Manchester Metropolitan University, s.parry@mmu.ac.uk, @drSarahParry. Practice Fellow and HCPC registered clinical psychologist. Sarah has worked extensively in the children’s residential care sector and works in practice with young people experiencing anxiety, psychosis and post-traumatic stress. ORCID 0000-0002-5666-1997

2Dr Filippo Varese, University of Manchester, Clinical Senior Lecturer in Psychology, and HCPC registered clinical psychologist. Since 2018, Filippo has been the Director of the Complex Trauma and Resilience Research Unit (C-TRU). C-TRU is a collaboration between the University of Manchester and Greater Manchester Mental Health NHS Foundation Trust, which aims to improve understanding and clinical innovation of trauma, complex trauma and related mental health needs in the NHS. ORCID: 0000-0001-7244-598X

*Corresponding author information: Dr Sarah Parry, M15 6GX, England, UK (e-mail: s.parry@mmu.ac.uk).

Keywords:

Hearing Voices, Auditory Hallucinations, Parent’s Narratives, Qualitative

Data availability statement: The data that support the findings of this study are available from the corresponding author upon reasonable request for a limited period.

Funding: Health Research Accelerator Grant

Acknowledgements: The authors would like to thank all the parents and carers who shared their stories. Special thanks to Voice Collective, the NHS Trusts, and Professors Rebecca Lawthom and Tony Morrison who supported recruitment and participant engagement.

Translational output film: https://www.youtube.com/watch?v=ZVlevja9sEs

Accepted 20th November 2020

Abstract

Background Despite the vital role parents play in caring for children with auditory hallucinations, very little research has garnered their experiences, opinions and recommendations for improving service design and delivery.

Methods 132 participants (*M*age=39.11; SD=8.50) from 14 countries completed an online qualitative survey, providing rich reflective narratives about their individual and systemic experiences of caring for a child with auditory hallucinations. Narratives were analyzed through a Foucauldian-informed narrative analysis, which recognized the influence of internalized stigma and societal narratives that surround hallucinations across Western cultures.

Results Four emancipatory narratives provide novel insights into the experience of caring for a young voice-hearer. Participants discussed their first thoughts and reactions, which were often influenced by negative societal narratives surrounding voice-hearing and fears for the future, as well as how a lack of tailored systemic support could adversely affect family functioning.

Conclusions Parents require greater access to, and inclusion in, intervention pathways within mental health services. Mothers may require additional resource due to a lack of systemic support and risks to their wellbeing as they care for their child. Participants recommend changes for clinical care, including earlier early intervention pathways for young children, easily accessible online information, support groups and parent training programs.

Keywords: Hearing Voices, Auditory Hallucinations, Parent’s Narratives, Qualitative

"Listen to the parents… Really listen to the child!" Family Narratives of Supporting Children Hearing Voices

The rapid biopsychosocial development of young people during adolescence makes it a challenging time for many, especially those who experience additional developmental challenges, such as early-onset psychosis (Morrison, et al., 2020). Early-onset psychosis before the age of 18 is recorded 5·9 young people per 100,000 people in the United Kingdom (UK; Boeing, et al., 2007). However, the presence of symptoms associated with early-onset psychosis, such as voice-hearing, are thought to affect many more young people who do not seek help from mental health services (Maijer, et al., 2019; Parry & Varese, 2020). Prevalence estimates range from 7.5% to 35% in youth populations (Kelleher, et al., 2012; Maijer, Palmen, & Sommer, 2017), suggesting that much more research around voice-hearing as a phenomenon separate to psychosis in childhood is appropriate and necessary.

Outcomes are particularly poor for young people diagnosed with psychosis and access to suitably tailored youth-focused interventions are limited in their availability and scientific evidence-base due to a scarcity of research with young people and their families to inform tailored protocols (Immonen, Jääskeläinen, Korpela, & Miettunen, 2017; Stafford, et al., 2015). Antipsychotic medications, cognitive behavioral therapy (CBT) and family therapy are recommended treatments for early-onset psychosis due to findings from research conducted with adults (National Institute for Health and Care Excellence guidelines; NICE; CG155). Recent enquiry with clinicians in the UK has highlighted dichotomously that CBT and family therapy are often viewed as secondary interventions to antipsychotic medication, although clinicians worry about prescribing antipsychotics to young people (Byrne, et al., 2020). Further, there are wide ranging concerns around the safety and suitability of antipsychotic medications for young people (Correll, et al., 2009; Krause, et al., 2018). Recently, a triple-blind randomized controlled noninferiority trial demonstrated no clinically significant benefits to antipsychotic medications (risperidone 1mg or paliperidone 3mg) for 15-25-year-olds compared to the placebo medication (specially created to match appearance, taste, and packaging; Francey, et al., 2020), illustrating the need for good quality psychologically-informed alternatives.

Non-pharmacological alternatives are not only important for young people assessed as at risk mental state of emerging and early-onset psychosis but also young people with unusual sensory experiences who often experience symptom-related distress due to the stigma surrounding symptoms associated with psychosis (Laurens & Cullen, 2016). Reassurance as an intervention may be especially important for younger children, where there are phenomenological similarities in experience between imaginary companions, dialogic inner speech, and symptoms often associated with psychosis in adolescence, such as hearing voices (Fernyhough, Watson, Bernini, Moseley & Alderson-Day, 2019).

Research with parents of young people who experience voice-hearing is exceptionally scarce, which also limits the evidence-base from which to inform support for young people and their families. Developing an understanding of the parents/carers who care for young people is essential as the reactions of significant adults towards children's disclosures around voices can influence the wellbeing of the child and the nature of the voice in terms of form and voice content (Parry & Varese, 2020). A small study of parents with children in a therapeutic community for young people with psychosis indicated that parental exclusion and feelings of shame and guilt could further contribute towards relational instability (Romelli & Pozzi, 2016), which could further increase the risk to wellbeing of a young person at a delicate developmental stage with additional challenges.

Parents of adult children who hear voices have stressed the need for better communication between themselves and mental health services, formal support and recognition for the importance of their caring role (Landon, Pike, Diesfeld & Shepherd, 2016). One of the few studies to explore parent and child experiences of accessing support for voice-hearing within Child and Adolescent Mental Health Services (CAMHS) in the UK's National Health Service (NHS) with 32 young people and 27 parents, indicated that many parents feel lost within CAMHS, unheard and wished for normalizing holistic care (Kapur, et al., 2014). Consequently, the current study sought to gather reflexive narratives from parents and cares of young people who hear voices, developing a rich and novel insight into collective experiences to inform service design, delivery and future recommendations for research and practice.

Methods

Design and Procedure

Qualitative survey data around voice-hearing has previously been successfully elicited within the voice-hearing community (e.g. Woods, Jones, Alderson-Day, Callard & Fernyhough, 2015) and narrative survey methods can be beneficial across a range of popultaion (Shkedi, 2004). Consequently, a qualitative narrative survey was developed and people with lived experience of voice hearing and community support workers reviewed the research protocol and all participant facing documents prior to ethical review. The research program was reviewed and approved by an academic interdisciplinary Research Ethics Committee (REC) and a pediatric English National Health Service (NHS) REC.

Participants could opt-in to the online survey through opportunity sampling and the survey was promoted through the NHS, peer-support groups (e.g. Hearing Voices Network, Voice Collective) and social media. Parents and guardians were invited to take part if they identified as caring for a child/young person who heard voices that others could not. Their children were not required to have received a formal diagnosis or be connected to a mental health service as research demonstrates relatively few people who hear voices engage with health services (e.g. Maijer, Palmen, & Sommer, 2017) and that further research is required within community samples (Luhrmann, et al., 2019). Once participants entered the study hosted by Qualtrics, they were provided with information about the research program, support information, a mandatory consent form, contextual and demographic questions, as well as explorative qualitative questions to elicit their personal narratives (Table One).

Table One: *Question posed to participants*

1. What is your relationship to the young person who hears a voice/voices?
2. How old is the young person you know who hears a voice/voices? (In years):
3. How long have you been caring for the young person you know who hears a voice/voices? (In years/Months):
4. How long has your child or the young person you look after heard voices?
5. Have you sought support for them through mental health services or other statutory and non-statutory services in relation to these experiences?

Your age
Gender
Ethnicity
Country of current residence
Nearest city/state/province

Qualitative Questions

1. How old was the child/young person when they told you they heard a voice?
    - Did they tell you straight away?
    - What were your thoughts at the time?
    - What was your response?
    - With hindsight, would you have responded differently when you first became aware of the voice hearing experiences

2. How do you feel about the voice/voices they hear?

3. Why do you think they hear the voice/voices?
4. Do you feel able to talk to anyone about the voice hearing experiences of your child/family member?
5. Have there been any wider relational and/or social impacts on the family as a result of the voices?
6. What support would be helpful to you as a parent/guardian of a young person who hears voices?
7. What would be your advice for other parents/guardians of a young person who hears voices?
8. Based on your experiences, what would be your advice for children's mental health practitioners and services?
9. Do you have any other thoughts, feelings or comments you would like to write about?

Participants

132 participants (*M*age=39.11; SD=8.50) completed most of the survey. Participants were advised in the information sheet and at the start of the survey that they could say as much or as little as they wished and that some questions may be more relevant to them than others. Of the sample, 132 stated their relationship to the child (75%=mothers, 7.6%=fathers, 4.6%=unspecified parent, 2.3%=step-parents, 1.5%=adoptive parents, 1.5%=siblings, 0.8%=grandparents, 6% other unspecified) and 120 participants responded with their gender (F=84%, M=10%, NB=0.8%, 5% preferred not to state). Only 32.4% of participants stated they had sought help from mental health services or other statutory and non-statutory services, leaving 67.6% not seeking help. A summary of the contextual and relational data is provided in Table Two, although the question, '*How long has your child or the young person you look after heard voices?'* was not answered with a specific duration in all instances. For example, one participant stated: "as long as she could speak". Therefore, it was not possible

to accurately translate all answers into numerical data and the *n* is provided for each response to show representation within the sample.

Table Two: *Contextual Summary*

Question	*n*	*x* (years)	S	Min	Max
How old is the young person you know who hears a voice/voices?	123	9.90	4.01	4 years	22 years
How long have you been caring for the young person you know who hears a voice/voices?	132	9.35	4.37	6 months	22 years
How long has your child/the young person you look after heard voices?	101	1.85	8.50	1 day	10 years

Notes: n = sample; x = mean; s = standard deviation

Participants were asked for their ethnicity and country of current residence in their own words. 28.4% of participants self-identified as white, 19.3% as white British, 18.3% Caucasian, 8.3 British, 4.6% Australian, 4.6% Hispanic, 2.8% Anglo-Australian, 2.8% European, two participants described themselves as Black, two as Irish and two Indian. Finally, one participant self-described as African American, one as Asian, one Black British, one Czech, one Jewish and one Filipino. Overall, most participants lived in England (39.5%) and the United States of America (USA; 36.8%), with 12 participants based in Australia, five in Canada, and one participant in each of France, the Ivory Coast, New Zealand, Northern Ireland, Norway, Portugal, Saudi Arabia, South Africa, Sweden and Wales. Participants were invited to provide their own pseudonym to protect their identity and some participants provided feedback that the process of participation had been beneficial, for example, “There isn't much out there on the topic, but finding this webpage really helped me to calm down a bit and I was grateful that my initial response have all been supportive and positive” (Nine).

Analytic Approach

Increasingly, qualitative methodologies offer a critical epistemological platform for analyses, such as interpretative phenomenological analysis, critical narrative analysis and Foucauldian approaches to narratives. Following a review of narrative approaches to qualitative survey data and identification of successful approaches (e.g. Rooney & White, 2007; Shkedi, 2004), , a six-step analytic framework was developed (see Parry & Varese, 2020, S2)to construct a Foucauldian-informed narrative analytic framework (FNA) to capture and explore ideographic and systemic elements of participants’ reflective narratives within their sociocultural milieu. We considered it important to use a FNA specifically due to the socio-cultural and biomedical assumptions surrounding voice-hearing that are so prevalent and easily internalized within Western cultures.

The framework began observing individual characteristics within ideographic reflective narratives, which included close attention to phenomenological features of individual perspectives; progressing to explore relationships, language and power structures; epistemologically accepting that biopsychosocial environments were likely to have influenced meaning-making processes throughout the reflective narratives. At three time points within the data collection and analytic process, parts of the anonymized data set were analyzed separately by three postgraduate psychology students to assess the parity and consistency of the emerging narratives in relation to analytic stages four and five (Individuality and Commonality; Constructing a Resolution), before the researchers conducted a final review to prepare the phenomenological and emancipatory narratives within phase six of the framework. Quotes are presented verbatim as typed by the participants to preserve their authenticity.

Results

Chapter One: First thoughts and reactions – I'm a parent, I worry. I'm afraid and I don't know how serious this is or how to react" (Juliette)

The first question posed to parents was in relation to their initial thoughts when their children told them about voice-hearing, which ranged from curiosity to disbelief and fear. For example, "First response was disbelief, then I thought maybe he had a gift of hearing spirits, now just panic" (Rowen); "...frustrating to tell when he's actually hearing something and frightened or when he's putting it in for attention." (Lou). There was also some evidence that participants in the UK and USA in particular drew upon biomedical and spiritual conceptualizations of voice hearing, for instance, "she might be a bit crazy" (Nine); "Is it a chemical thing. some kind of different wiring in the brain or a spiritual link to a past life" (Beano); "Could it be a waking dream, a mental disorder, or even the supernatural? I don't know" (Jolene); "There was a tiny worry that it may have been religiously affiliated, as in a spirit or demonic presence..." (Grant).

There was a significant concern amongst many parents that voices were a sign of mental illness, especially for those who associated voice hearing with diagnoses within the family, "Possibility of mental illness given that the child's aunt was diagnosed with schizophrenia" (Vanessa); "Thought it was a bit strange and psychotic" (Alf); "Concerned it's a serious mental health problem" (Shazza); "I was terrified […] My sister has severe schizoaffective disorder (constant auditory hallucinations) and my father had bipolar disorder" (Cyclops).

Other participants questioned their child’s interpretation of their experience, for instance “I thought she must have been dreaming” (Jolene). The majority expressed concern, although also recognized the importance of their role to offer support: “Fear. But to stay calm and make sure that I did not make him feel weird for it” (Aidonis); “I was somewhat concerned […] wasn’t sure what to say really but didn’t want him to stress about or think it was a bad thing” (Molly); “I reassured her she was normal and […] thought it was because she was feeling anxious at the time.” (Diane).

One of the main causes of anxiety amongst the participants was caused by feeling unprepared to help their child: “A little scared because I don’t understand why” (Anne Marie). Following the surprise of the initial disclosure, many participants reflected upon how they responded to their child: “I acted too concerned and too much like it was abnormal.” (Mum); “I feel now like I could have been more reassuring […] but at the same time it’s obvious these voices are scaring him...” (Halee); “Maybe I would have been a little more open to asking questions […] so I can better understand him. Of course research came after the initial encounter” (Cornelius).

Following the ‘initial encounter’, participants reported feeling ill-equipped to support their child: “...a bit powerless, because he finds them distressing and there isn’t anything I can do to make them stop” (Cyclops); “I feel totally clueless with what to do for the best!” (Halee). Participants also reported struggling to find suitable help: “I don’t know where to turn.” (Aidonis), which increased their anxieties. A lack of reliable information also led many participants to worry for their children’s futures: “I thought he has mental health problems and was scared for his future” (Olivia); “...I have serious concerns that he will become suicidal from a young age.” (Sarah); “...deeply truly fear that she will end up rejected by society, unemployed, filthy, wild, on the streets” (Grant). These concerns for the future increased parental anxiety and many looked for sources of support: “I want to know other parents’ experiences and how they supported their children” (Diane).

Chapter Two: Engaging with services and help-seeking - “our experience has taught me that adequate supports are not there” (Jane)

Some participants actively avoided medical and mental health services for fear of the outcome: “I’d like to talk to a Dr but I’m worried they’ll dismiss it or I won’t get any support” (Halee); “GPs will not be very informed, will not refer you to the right services, will offer medication as a ‘easy’ effective solution” (Hetty). Others were concerned that help-seeking could exacerbate their child’s anxiety, “I have real doubts about formal mental health services being able to help… seeking advice would create stress for my son and make him more anxious about the voices!” (Ozone). However, some participants found suitable help for their children in the form of talking therapies, “We have a wonderful counselor for her” (Grant), although others wanted further support from people with lived experience: “Other people's experiences. How to live positively with it.” (Sedrick); “a parents group and specialist parenting training” (Ella); “Online advice; more awareness of the condition, in GPs, media. Support groups, for the young people and for parents/carers and siblings” (Kelvin).

Participants with younger children had particular difficulties accessing support across the sample: “There is a massive gap in services with zero services being available for someone experiencing voices so young” (Free03). In countries such as the UK where specialist support isn’t readily available for voice-hearing until the age of 14, sourcing support for younger children was especially difficult: “I’ve had a huge struggle […] it seems like mental health support for young people is almost non-existent and I just can’t understand how that’s OK” (Halee). Some participants discussed their experiences with UK CAMHS in particular: “Fight for support don't give up. Camhs is a long wait and hard to get through to”

(MsX); “It would of been very helpful for the CAMHS psychiatrist to spend a little more time with us as parents to explain things” (Tommy).

Additionally, it was recognized across many narratives that children’s ability to engage in typical school activities could also be impeded: “sometimes he struggles to concentrate […] they are most frequently described during school tests” (Mum); “She has problems behaving in school – the voices tell her to act out” (Grant). Participants discussed the potential role of community and educational support to provide systemic care around the young person: “support in school and now in college advocacy” (Ella); “camhs should be more in the community. they shouldn't expect young people to come to their offices. schools are putting too much pressure on young people” (Lilly); “Getting the voice collective information was a huge help to us initially .... something we, as parents, did not get from CAMHS.” (Elizabeth). Overall, the role of community-based peer support and school-based programmes was highlighted by a number of participants:

> Speak to Voice Collective as they truly understand, don't judge, really listen to you and offer some practical advice… Listen to parents, find a better way of communicating with the child and offer practical support in the interim prior to assessment. For practitioners to get rid of the myth that a child can be too young for any potential mood or psychiatric condition to be present - surely early intervention is key!
>
> (Free03)

Participants provided recommendations for service providers in terms of how they could inclusively provide support for the family: “Involve family in treatment options, and how to best support their child” (Maria D); “Listen without trying to automatically diagnose it as schizophrenia” (Jolene); “Look at research and don’t jump to medication” (Cornelius); “Treat each child as an individual. Don’t suggest medication immediately” (Maria D); “...don’t brush it off and help the family understand” (Brandy); “Listen to the parents, Listen to the parents. Listen to the parents" (Charlie); "Listen, really listen to the child. Don't be dismissive. There are underlying reasons why they are hearing voices and it is due to stress or trauma or something, not a mental health issue per se" (Yogamom). Within the narratives, parents described how their own wellbeing could be compromised by being excluded from the provision of care for their child. Parents wanted information and guidance as to how they could better support their child and wider family.

Chapter Three: Systemic influences and relationships - "Symptoms of stress, anxiety and trauma can occur in parents going through this experience so it's vital that there's more education, openness, acceptance and support. Breaking down the stigma, isolation and fear is essential" (Grace)

An important emancipatory narrative within the participants' data referred to the impact of supporting a child who hears voices upon the family. Participants explained how they experienced distress due to their concerns for their child: "I listened and we talked about it. I was very calm on the outside, but … It was not the voices that bothered me as much as the violent content and distress it was causing my child" (Jane). Some mothers, the majority of the participant sample, also struggled to access support within the family system: "I am hesitant to share this with his dad as he would think the worst and potentially make my son feel insecure" (Beano); "My husband (their dad) brushes it off. I haven't told anyone outside our immediate family" (LJ). There could be difficulties with siblings too: "physical interactions with sibling, exacerbated emotional responses" (Barry); Brother and sister don't understand why she talk and shouts at a blank space In a room" (Lizzy). Overall, mothers in particular reflected upon how they were providing support to their families, although often felt very isolated and unsupported themselves.

Numerous accounts from participants detailed the relational and familial difficulties that could be present alongside supporting their child, "As parents we argued behind closed doors about how we should react" (Drew). For some, marital stress was emerging as a concurrent related stressor:

> The strain on my relationship with my husband is great. I take the major role in caring/hospital appointments/medication etc. He does not notice signs when things are deteriorating. I do not think we will stay together because of the difficulties of caring for a young person who hears voices that are detrimental on their life. I have been unable to continue working due the pressures/time constraints and unpredictability of the illness
>
> Frances

Chapter Four: Meaning making and interpretation – "a coping mechanism to deal with pressure and stress and as a reaction to bullying" (Drew)

In parallel to parental anxieties for their children's health and family functioning was a recognition that the voices could serve a range of useful functions: "My son is becoming very open about his friend" (Beano); "I am glad that she is calmed by them" (Nine). There were also elements of comforting spirituality within some narratives, for example "they were visiting them from heaven" (Curious); "it's a cool thing... almost like a guardian angel […] protect you from danger and navigate you through difficult situations" (Beano). Overall, a small percentage of respondents narrated how the voices could have a positive presence within their children's lives.

However, most parents reported concerns, "Some of the voices she hears are not nice" (Mrs Mini Apple); "...telling him to do bad things" (Alf); "...quite scary for my child and myself […] late in the evening […] I hear screaming because they think someone is talking to them" (Lou); "He told me the voices were like death voices and one told him to kill himself." (Halee); "Very concerned. He says they sound like suffering." (Wissa); "they tell him to steal knives and sneak out so fear for his safety.” (Rose); “Concerned, as she has said that the voices mainly instruct her to do something wrong or mean.” (Maria D). Generally, the nature of the voices, rather than the presence of voices, caused the greatest distress for participants.

Participants also tried to contextualize their child’s voices within their life experiences, for example, “His father and I separated […] He has separation anxiety and perhaps the voices are a way to cope with feeling alone” (Molly); “They lost their great-grandfather and parents and it was pretty traumatic” (Curious); “I assumed it was a way of processing information or shifting responsibility externally” (Amy); “perhaps going through stressful period at school...” (Alf). For some participants, there were critical incidents that they attributed to the onset of the voices: “The voices started after […] bullying by an older child at school […] persisted now for six years, so perhaps they would have started anyway […] can’t identify any trigger for them...” (Cyclops); “My daughter was an elite gymnast under a lot of pressure […] I could figure out how it may have started with my daughter...” (Halee); “...he has seen his father been abusive towards me and we have moved a lot in his young life” (Cornelius); “I think it developed out of her feelings of helplessness following my battles with chronic illness” (Jane); “Bullying she has suffered” (Lizzy); “Her dad and I have been separated […] she has consistently struggled with that […] when I am low she feels unsettled” (Hetty). Interestingly, one participant discussed that her young daughter’s voices had only become problematic when there had been an illness in the family, indicating the changing nature of auditory experiences over time, “The voices turning negative coincided with my mother's terminal illness so I wonder if this played a role” (Face). Formulating the presence of voices within an experiential context appeared to provide many participants within the sample with some comfort as they could attribute the onset of voices to circumstances in the past, rather than present illness or other less tangible influences (e.g. spiritual possession).

Personal characteristics of the child were also recognized as factors: “He over thinks a lot of things. His brain could be going a million miles an hour” (BB); “My daughter has Asperger's syndrome: I feel that the voice hearing is co-morbid; a naturally developed coping mechanism (social difficulties, etc.)” (Kelvin). Creativity was another feature that was mentioned in some participant narratives, for example, “she said they were helping her to write songs and melodies” (Nine); “I think he has just always been very auditory and creative. I think that hearing voices in childhood was part of that creative process, from babyhood onwards he would 'freeze' when he heard sounds” (Ella); “I know that the onset of adolescence was very hard for her. The school system separated her from her childhood friends” (Elizabeth); “Imagination sound distortion” (KS). Overall, the factors participants identified could diminish or exacerbate their distress in relation to the presence and nature of the voices, depending upon how past or present the attributions were and how much control parents felt they had over the identified stimuli.

Concluding Discussion

Reflective narratives were sought from parents and cares of children and young people who hear voices to gain novel insights into their experiences. Parental stress was exacerbated by a number of factors, including the attribution of voice-hearing to mental illness, the child’s distress in response to the voice(s), feeling unprepared to help their child, feeling isolated and unsupported by a spouse and mental health services, and a concern that seeking help could exacerbate the child’s anxieties. Despite these challenges, parents and carers recognized the important role they had to play in helping the child remain as calm as possible and adopt a curious position towards their voices. The importance of acceptance of voices and reassurance from parents/carers to reduce the child’s anxiety were raised in Escher et al.’s paper in 2004, although participants of the current study highlighted this is sometimes difficult when they feel unprepared and while awareness of voice-hearing is limited. Chapter four of the analysis discusses the processes through which parents looked for meaning and context for their child's voices, which mirrors requests from adult voice-hearers to have the opportunity to discuss the content and meaning of their voices as an important feature of treatment and engagement with services (Coffey & Hewitt, 2008).

Participants had a number of recommendations, which included clinicians providing parents with clear information, reassurance and explanation as to how they could practically support their child, thereby reducing parental distress. Participants stated early intervention should be available earlier for younger children and wanted information to be easily available, increasing awareness of the phenomena. Participants also wished to benefit from the experiences of other parents, siblings and young experts-by-experience. Peer support could be nurtured outside of mental health services through online forums and community groups. Within the data, UK participants cited barriers to accessing helpful services through the NHS. Further, participants across the international sample reflected on a lack of tailored services and a desire for peer community support. The predominantly online nature of Voice Collective, a community-sector group mentioned by name by a small group of participants, indicates online support is acceptable and accessible. Online support services could address geographical barriers to accessing support. It would be exciting to see further international research in this area to share good practices and resources amongst countries and communities.

Finally, participants recommended providing information as to how young people could live well with voices. Parent training groups were recommended as beneficial systemic interventions. These recommendations are especially useful for designing specialist support for younger children and families, groups often excluded from research around voice-hearing. However, due to the sample size and exploratory nature of this study, further research is required with young people and families to explore how psychiatric comorbities (e.g. anxiety, depression, post traumatic stress) and wider family functioning may influence the acceptability and efficacy of such approaches (Downs, et al., 2017).

In the context of research with children and young people who hear voices, parental accounts of phenomenological features of distressing voices are similar in terms of the directive form they take, for example, “told him”, “they tell him”, “instruct her” (Parry & Varese, 2020). These directive features seem to be a key phenomenological aspect of frightening voices that differentiate them from other auditory experiences. Further, witnessing their child’s distress exacerbated parental distress and reduced familial resilience. Research with adolescents who hear voices has indicated that parental responses to the presence of auditory hallucinations can alter the nature of the voices in terms of content and distress (Parry & Varese, 2020). Therefore, family interventions should be provided to offer support for parents, practical strategies that can be employed at home, school, and reduce overall distress in response to the presence of voices within the child’s social milieu.

A recent feasibility study of early-onset psychosis indicated that family therapy could be less acceptable to young people than individually delivered CBT (Morrison, et al., 2020), although the findings of the current study suggest helpful systemic interventions could be provided to parents directly, concurrently to support offered to the child, mitigating the requirement for combined psychological delivery to young people and parents. Additionally, it is recognized that caring for a family member with significant mental health difficulties can have a detrimental impact upon the carer’s social, emotional and economic quality of life (Boydell et al. 2013; Parabiaghi et al. 2007) and relationships (Awad & Voruganti 2008), which was described in chapter three of the current study. Consequently, family therapy interventions need to look beyond the young person to their main carer(s) and support them to provide optimal care with support, to enhance the resilience of the young person and family surrounding them.

Importantly, the option of providing support to parents assumes parents are aware of their child's experiences of voice-hearing. Research with adolescents suggests many young people do not disclose their experiences of voice-hearing to their parents (Parry & Varese, 2020), with internalized stigma around voice-hearing a recognized barrier to disclose (Vilhauer, 2016). Adolescents in the general population generally confide and disclose less to their parents with age, declining gradually in frequency during adolescence for 82% of young people (Padilla-Walker, Son, & Nelson, 2018), highlighting an additional barrier to accessing suitable support for voice-hearing in adolescence. The same study indicated that the parent-child relationship was an indictor for disclosure, which indicates that parent training programs should focus on nurturing positive relationships and interactions, as has been found to be beneficial in parent-child interventions with younger children (e.g. Parry, Simpson & Weatherhead, 2018).

The online nature of the current study meant that it was not possible to ask follow-up questions to elicit further detail and examples from participants, although the methodology did ensure that a relatively substantial participant sample informed the interpretations and conclusions. Further, this approach also demonstrates that rich reflective narratives can be gathered through qualitative online platforms, reducing participatory barriers for marginalized participant groups. As primary research with a self-selecting recruitment strategy and over-representation of white, female participants from the UK and US, generalizations are limited. However, this novel and exploratory study has provided a number of recommendations for clinical practice and future research, which would improve treatment options and outcomes for voice-hearing children and their families across social milieus.

Practitioner Summary

- Parental wellbeing and familial resilience could reduce voice-related distress for young people, although the mechanisms underpinning this are not well understood.
- Parents/carers play a vital role in how their children experience voices and the auditory nature of voices, although often feel disempowered and under-skilled to provide support.
- Participants recommend providing inclusive community and school-based family support, earlier early intervention pathways for young children and practical support prior to assessments so they are better prepared to support their child at home.
- Clinical interventions that attend to enhancing positive features and interpretations of voice hearing, building coping skills and parental wellbeing could reduce familial distress more efficiently than interventions that focus on eliminating the presence of voices.

Disclosure statement: The authors report no conflict of interest

References

Awad, A.G., & Voruganti, L. (2008). The burden of schizophrenia on caregivers: a review. *PharmacoEconomics, 26*(2), 149–162. doi:10.2165/00019053-200826020-00005.

Boydell, J., Onwumere, J., Dutta, R., Bhavsar, V., Hill, N., Morgan, C., & Fearon, P. (2013). Caregiving in first-episode psychosis: social characteristics associated with perceived 'burden' and associations with compulsory treatment. *Early Intervention in Psychiatry*, *8*(2), 122-129. doi:10.1111/eip.12041.

Byrne, R.E., Reeve, S., Bird, J.C., Jones, W., Shiers, D., Morrison, A.P., Pyle, M. & Peters, S. (2020). Clinicians' views of treatment types for first episode psychosis delivered in a randomised controlled trial (MAPS). *The Lancet.* doi: https://doi.org/10.1016/j.eclinm.2020.100421

Coffey, M., & Hewitt, J. (2008). 'You don't talk about the voices': Voice hearers and community mental health nurses talk about responding to voice hearing experiences. *Journal of Clinical Nursing, 17*(12), 1591-1600. doi:10.1111/j.1365-2702.2007.02185.x

Correll, C.U., Manu, P., Olshanskiy, V., Napolitano, B., Kane, J.M. & Malhotra, A.K. (2009). Cardiometabolic risk of second-generation antipsychotic medications during first-time use in children and adolescents. *JAMA, 302*, 1765–73.

Escher, S., Morris, M., Buiks, A., Delespaul, P., Van Os, J., & Romme, M. (2004). Determinants of outcome in the pathways through care for children hearing voices. *International Journal of Social Welfare, 13*(3), 208-222. doi:10.1111/j.1369-6866.2004.00315.x

Fernyhough, C., Watson, A., Bernini, M., Moseley, P., & Alderson-Day, B. (2019). Imaginary companions, inner speech, and auditory verbal hallucinations: What are the relations? *Frontiers in Psychology, 10*, 1665. doi:10.3389/fpsyg.2019.01665

Francey, S.M., O'Donoghue, B., Nelson, B., Graham, J., Baldwin, L., Yuen, H.P., et al. (2020). Psychosocial intervention with or without antipsychotic medication for first-episode psychosis: a randomized noninferiority clinical trial. *Schizophrenia Bulletin, 1*: sgaa015.

Immonen, J., Jääskeläinen, E., Korpela, H. & Miettunen, J. (2017). Age at onset and the outcomes of schizophrenia: a systematic review and meta-analysis. *Early Intervention in Psychiatry*, *11*, 453–60.

Jardri, R., Bartels-Velthuis, A. A., Debbane, M., Jenner, J. A., Kelleher, I., Dauvilliers, Y. & Fernyhough, C. (2014). From phenomenology to neurophysiological understanding of hallucinations in children and adolescents. *Schizophrenia Bulletin, 40*(4), 221-232. doi:10.1093/schbul/sbu029

Kapur, P., Hayes, D., Waddingham, R., Hillman, S., Deighton, J., & Midgley, N. (2014). The experience of engaging with mental health services among young people who hear voices and their families: A mixed methods exploratory study. *BMC Health Services Research, 14*(1), 527-527. doi:10.1186/s12913-014-0527-z

Kelleher, I., & Cannon, M. (2011). Psychotic-like experiences in the general population: Characterizing a high-risk group for psychosis. *Psychological Medicine, 41*(1), 1-6. doi:10.1017/S0033291710001005

Krause, M., Zhu, Y., Huhn, M., Schneider-Thoma, J., Bighelli, I., Chaimani, A., & Leucht, S. (2018). Efficacy, acceptability, and tolerability of antipsychotics in children and adolescents with schizophrenia: A network meta-analysis. *European Neuropsychopharmacology, 28*(6), 659-674. doi:10.1016/j.euroneuro.2018.03.008

Landon, J., Pike, B., Diesfeld, K., & Shepherd, D. (2016). The experiences of parents providing support to adult children with schizophrenia. *International Journal of Mental Health and Addiction, 14*(4), 385-399. doi:10.1007/s11469-016-9643-9

Laurens, K. R., & Cullen, A. E. (2015;2016;). Toward earlier identification and preventative intervention in schizophrenia: Evidence from the London child health and development study. *Social Psychiatry and Psychiatric Epidemiology, 51*(4), 475-491. doi:10.1007/s00127-015-1151-x

Luhrmann, T. M., Alderson-Day, B., Bell, V., Bless, J. J., Corlett, P., Hugdahl, K. &Waters, F. (2019). Beyond trauma: A multiple pathways approach to auditory hallucinations in clinical and nonclinical populations. *Schizophrenia Bulletin, 45*(1), 24-31. doi:10.1093/schbul/sby110

Maijer K, Hayward M, Fernyhough C, et al. (2019). Hallucinations in children and adolescents: an updated review and practical recommendations for clinicians. *Schizophrinia Bulletin, 45*(l), p. 5–23. Doi: 10.1093/schbul/sby119.

Maijer, K., Palmen, S. J. M. C., & Sommer, I. E. C. (2017). Children seeking help for auditory verbal hallucinations; who are they? *Schizophrenia Research, 183*, 31-35. doi:10.1016/j.schres.2016.10.033

Morrison, A.P., Pyle, M., Maughan, D., et al. (2020). A feasibility randomised controlled trial comparing antipsychotic medication to psychological intervention to a combined treatment in adolescents with first episode psychosis: The MAPS trial. *Lancet Psychiatry*. https://doi.org/10.1016/S2215-0366(20)30248-0

National Institute for Health and Care Excellence. *Psychosis and schizophrenia in children and young people: recognition and management*. Clinical guideline CG155. Oct 26, 2016. https://www.nice.org.uk/guidance/cg155

Padilla-Walker, L.M., Son, D., & Nelson, L.J. (2018). A longitudinal growth mixture model of child disclosure to parents across adolescence. *Journal of Family Psychology, 32*(4), 475–483. https://doi.org/10.1037/fam0000369

Parabiaghi, A., Lasalvia, A., Bonetto, C., Cristofalo, D., Marrella, G., Tansella, M., & Ruggeri, M. (2007). Predictors of changes in caregiving burden in people with schizophrenia: a 3-year follow-up study in a community mental health service. *Acta Psychiatrica Scandinavica, 116*, 66–76. doi:10.1111/j.1600-0447.2007.01094.x.

Parry, S., Simpson, J. & Weatherhead, S. (2018). Changing Relationships through Interactions: Preliminary Accounts of Parent–Child Interactions after Undertaking Individual Parent Training. *Child and Adolescent Social Work Journal, 35*(6), 639–648. doi: 10.1007/s10560-018-0547-3

Parry, S. & Varese, F. (2020). Whispers, Echoes, Friends and Fears: Forms and Functions of Voice Hearing in Adolescence. *Journal of Child and Adolescent Mental Health*. doi: 10.1111/camh.12403, ISSN 1475-357X

Romelli, K. & Pozzi, G.O. (2016) Therapeutic community for children with diagnosis of psychosis: What place for parents? The relation between subject and the institutional 'Other', *European Journal of Psychotherapy & Counselling, 18*(4), 316-332. doi: 10.1080/13642537.2016.1260618

Rooney, C., & White, G. W. (2007). Consumer Perspective: Narrative Analysis of a Disaster Preparedness and Emergency Response Survey from Persons With Mobility Impairments. *Journal of Disability Policy Studies, 17*(4), 206–215. https://doi.org/10.1177/10442073070170040301

Shkedi, A. (2004). Narrative survey: A methodology for studying multiple populations. *Narrative Inquiry: NI, 14*(1), 87-111. doi:10.1075/ni.14.1.05shk

Stafford, M.R., Mayo-Wilson, E., Loucas, C.E., James, A., Hollis, C., Birchwood, M., & Kendall, T. (2015). Efficacy and safety of pharmacological and psychological interventions for the treatment of psychosis and schizophrenia in children, adolescents and young adults: A systematic review and meta-analysis. *Plos One, 10*(2), e0117166. doi:10.1371/journal.pone.0117166

Woods, A., Jones, N., Alderson-Day, B., Callard, F., & Fernyhough, C. (2015). Experiences of hearing voices: Analysis of a novel phenomenological survey. *Lancet. Psychiatry*, 2(4), 323.