Sussex Research Online

"That little doorway where I could suddenly start shouting out": barriers and enablers to the disclosure of distressing voices

Article (Accepted Version)

Bogen-Johnston, Leanne, de Visser, Richard, Strauss, Clara, Berry, Katherine and Hayward, Mark (2017) "That little doorway where I could suddenly start shouting out": barriers and enablers to the disclosure of distressing voices. Journal of Health Psychology. ISSN 1359-1053

This version is available from Sussex Research Online: http://sro.sussex.ac.uk/id/eprint/73110/

This document is made available in accordance with publisher policies and may differ from the published version or from the version of record. If you wish to cite this item you are advised to consult the publisher's version. Please see the URL above for details on accessing the published version.

Copyright and reuse:

Sussex Research Online is a digital repository of the research output of the University.

Copyright and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable, the material made available in SRO has been checked for eligibility before being made available.

Copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

Title

"That little doorway where I could suddenly start shouting out": barriers and enablers to the disclosure of distressing voices

Authors:

Leanne Bogen-Johnston¹, Dr Richard deVisser¹, Dr Clara Strauss¹, Dr Katherine Berry², Dr Mark Hayward¹

¹University of Sussex, Falmer, England

²University of Manchester, Manchester, England

Disclaimer

The views expressed in the submitted article are those of the authors and not an official position of the institution.

Corresponding Author:

Dr Mark Hayward

Abstract

Hearing distressing voices is a key feature of psychosis. The time between voice onset

and disclosure may be crucial as voices can grow in complexity. This study investigated

barriers and enablers to early voice disclosure. Interviews with 20 voice hearers

underwent Thematic Analysis. Beliefs about the effect of disclosure on self and others

acted as a barrier and enabler to voices being discussed. Voice hearing awareness

should be increased amongst young people, the public and care services. To support

earlier disclosure measures need to increase skill amongst those likely to be disclosed

to.

Keywords: hallucinations, voice hearing, psychosis, schizophrenia, disclosure.

Introduction

The Duration of Untreated Psychosis (DUP) is the time between the emergence of the first psychotic symptom and the start of effective treatment (Padilla et al., 2015). Longer DUP is associated with poorer outcomes, and shorter DUP with better outcomes (Padilla et al., 2015). Consequently, there is a need for early detection of first-episode psychosis to reduce DUP (Penttila et al., 2014; Yung et al., 2007).

Psychotic disorders are typically preceded by low-level signs of psychosis, a prodromal at-risk mental state (ARMS) (Yung and McGorry, 1996). Due to fears of 'going mad' and negative reaction from others, ARMS individuals often delay disclosure and help-seeking (Byrne and Morrison, 2010). Those who progress to first-episode psychosis may still not seek help as they (and others) may not recognize symptoms of psychosis, deny warning signs of illness, or fear involvement with mental health services (McGlashan, 1999). Stigma, shame and a lack of mental health literacy are barriers for people seeking help for mental health problems (Bay et al., 2016; Gulliver et al., 2010). Furthermore, people tend to be unaware that voice hearing is a primary symptom of psychosis (Bay et al., 2016).

Although hearing voices is a common and often distressing symptom of psychosis (Aleman and Larøi 2008), many are reluctant to disclose voices at initial onset (Milligan et al., 2013). During the 'startle phase' when voices first occur, the hearer may not confide in others due to confusion about their experiences, the content of their voices or concerns about others' responses (Beavan et al., 2011; Boyd and Gumley, 2007).

Disclosure of voice hearing is often met with negativity and considered a sign of 'madness' (Romme et al., 2009). Negative stereotypes may be internalized, eliciting fear and apprehension of the stigmatizing costs of mental illness (Vilhauer, 2017).

Feared negative responses from others and internalized self-stigma may result in the hearer choosing to keep voices a secret (Boydell et al., 2006; Vilhauer, 2017). Milligan et al. (2013) proposed that help-seeking tends not to occur until the individual encounters a crisis regarding their experience with voices. During the time between onset and disclosure, voices may increase in complexity, with the hearer becoming progressively entrenched in the experience (Yung et al., 2007), intensifying the risk of delusional ideation and general psychopathology (De Loore et al., 2011). It is therefore important that help is sought as near to the onset of voices as possible, that barriers to early disclosure are understood, and that processes underlying the development of voices and delusions are explored.

The present qualitative study explored voice hearing in patients with first-episode psychosis from Early Intervention for Psychosis (EIP) services. Exploration of our research question - what are the barriers and enablers to the disclosure of distressing voices to family, friends and health professionals? – can inform both theories of disclosure (e.g. Disclosure Decision-Making Model; Green, 2009) and interventions designed to promote early disclosure.

Methods

Design

This study was part of a longitudinal mixed-methods project examining people's journeys with hearing voices over time, identifying different phases of managing voice hearing, and how these affect therapy.

In this study, we explored data from time one (T1) interviews designed to capture hearers' experiences of voices from time of onset. We employed a qualitative inductive approach to explore the disclosure of distressing voices among EIP service users. Due to the limited literature in this area, an inductive approach was appropriate

for gaining a deeper understanding of: why, when and how hearers decided to disclose voices; barriers or enablers to disclosure; and processes of seeking help. We took a critical realist perspective which argues that an external world independent of human consciousness exists, but that perception and understanding of it is socially determined (Danermark et al., 2002). Analysis paid attention to each participant's experiential truth, but acknowledged that participants sometimes described as real phenomena that may not have been real. TA was appropriate for exploring how understanding of these phenomena may have changed over time.

<u>Participants</u>

Participants were 20 purposively selected EIP service users in Sussex (n=17) and Manchester (n=3). EIP services are for people with first episode psychosis or 'at risk mental states'. They have a philosophy that focuses on managing symptoms rather than diagnosis and work within diagnostic uncertainty (Baird et al., 2012). Inclusion criteria required that service users were currently experiencing voices and had been doing so for at least three months. Service users were excluded on the grounds of organic illness or if voices were the result of substance misuse (as determined by EIP service practitioners). The sample consisted of 12 men and 8 women aged 19 to 35 years (M = 25. SD = 4.7; Mdn = 24). Age of voice onset ranged from 6 to 32 years (M = 19, SD = 6.8; Mdn = 19). Voice duration ranged from less than 1 year to 21 years (M = 7, SD = 6.8; Mdn = 3).

Procedures

All procedures were approved by the relevant NHS Research Ethics Committee. Prior to interview, clinicians discussed the study with service users and offered them a participant information sheet (PIS). The first author contacted service users (only those that had given permission) 24 hours after receipt of the PIS. Interviews were arranged at either NHS premises or at participants' homes.

After obtaining written informed consent, participants completed semi-structured interviews conducted by the first author. Open-ended questions allowed self-reflective and exploratory dialogue that generated new questions specific to each interview. The interview schedule reflected the aims of the broader study: to understand people's journeys with distressing voices over time. The research team discussed key areas of interest for the T1 schedule which focused on voice onset to current interview. Of relevance to this article were questions on: first voice experience; changes in experience; meaning and understanding ascribed to voices; seeking help; experiences of therapy; effects of voices; relationship with voices; and managing voices. Interviews lasted between 27 and 85 minutes and were digitally recorded.

Analysis

Inductive Thematic Analysis (TA) was conducted following Braun and Clarke's (2006) six-phase guide: 1) transcription; 2) reading and familiarization of transcript; 3) coding; 4) searching for themes; 5) reviewing themes; and 6) defining and naming themes. TA permitted an in-depth understanding of participants' voice hearing experiences with an exploratory non-theoretical approach. Although theories exist regarding barriers and enablers to disclosing stigmatized health conditions (e.g., Greene, 2009), the aim of the T1 interviews was not to test hypotheses, but to apply an inductive, bottom-up approach where themes emerged through participants' accounts of their experiences with voice hearing.

Interviews were transcribed verbatim and anonymised. Under the supervision of the research team, the first author coded each transcript systematically. The team reviewed the codes for patterns across the entire data set, which through a process of comparison and discussion, were classified into potential themes and entered into thematic tables and diagrams. The thematic tables and diagrams were reviewed independently and as a

group, and once consensus had been reached, themes were re-examined for links and grouped into higher order themes. The final set of themes was compared against the research question for meaning and significance.

Several attempts have been made to define quality in qualitative research: whereas there may be agreement about the broad issues, it is unlikely that any one set of criteria will be applicable to a diverse range of qualitative methods (Mays and Pope, 2000; Tracy, 2010; Yardley, 2000). Our approach to analysis was guided by Yardley's (2000) call for qualitative research to demonstrate sensitivity to context, commitment to rigorous analyses; transparency and coherence of methods and analysis; and an interest in research impact.

Findings

Analysis identified three higher order themes and their sub-themes. Each is described and illustrated below.

1. Effect of disclosure on the self

Participants gave much consideration to the pros and cons of disclosure. This often entailed a process whereby the presence of voices had to be acknowledged (What problem?), which also meant coping with the embarrassment of being a voice hearer and identifying as someone who has mental health issues (I feel too ashamed). In many cases, seeking help was not initiated until it became necessary and voices could no longer be endured alone (Reaching desperation).

1.a. What problem?

Part of the process of discussing voices involved acknowledging that a problem existed. In some cases (7/20), denial of voices, or that voices were an issue, was a less fearful option than admitting to a socially stigmatized experience. However, as the distress and a battle with voices continued, accepting their presence could no longer be

avoided. Participant 17 came to realise that in order to obtain relief they needed professional support, and that meant disclosure:

I'd been kind of running away from it, you know. Trying to ignore it for so long and I just didn't think that I could do that anymore. It's one of the reasons why I decided to, to get help a couple of years ago. But I struggled with it for quite a long time before I actually admitted that there was a problem. [P17]

Even when voices were acknowledged, if the experience did not significantly affect everyday life, then disclosure was not considered essential. Hearing voices intermittently was not recognized as a problem that required professional help. Voices were accepted as something that occasionally interfered with life, and needed no further enquiry:

Was [hearing voices] a problem then, or not?

I wouldn't have said so. I said now and again it became a problem like when it did distract me but not like now ... It didn't have a big massive impact on my life really. [P16]

However, as voices became more insidious and their frequency increased, P16 realized that voices were not trivial and were starting to become a major part of her life. Similar to other participants, her need to discuss them changed, as they could no longer be kept as a private experience: "it became really bad". Voices were now an occurrence that she could neither disregard nor live with.

For a few (2/20), voices alleviated the isolation of their social lives. Despite their negative voice content, voices were a constant companion that could relieve loneliness; the absence of this companion was a greater fear than the anguish caused by its presence. This acted as a barrier to voice disclosure. Remaining silent and existing

within a dysfunctional relationship with voices was preferable to disclosing and risk losing them:

I never really had many friends. Probably like one or two friends. And [the voice] was constantly there so I regarded it as a friend. Even though it was horrible it was there. And I say, I found myself talking to it and yeah, just I felt scared you know. I felt it, like it, it was there with me, like having your best friend with you constantly. Yeah, it's that, I don't really, I just felt scared of losing it. [P18]

1.b. I feel too ashamed

Participants (5/20) described how their understanding and perception of voices was either a barrier or enabler to disclosure. For some, beliefs about what it meant to hear voices evoked feelings of shame. The self-stigmatization of identifying as 'crazy' meant that hearing voices was an embarrassing experience best concealed:

Did you tell anybody?

No! No, I felt really ashamed 'cause you know when you think "ah, you're hearing voices" you felt a bit crazy and mental you know. So I kept it for myself for a very long time. It's not 'til erm, I told. I didn't tell my mu- I didn't tell my family for months, and months, and months. I kept it to myself. [P9]

For other participants, awareness of self-stigmatization and others' stigmatization prompted them to challenge unhelpful common beliefs and to begin a process of enquiry of finding opportunities to talk about voices:

I felt the need to talk about it because there's a lot of stigma around it and I was internalizing the stigma about it. So I felt like I had to sort of say "Well it doesn't mean I'm a psycho." So I try and explain it to people and see what

they thought it was as well. [P10]

1c. Reaching Desperation

As voices continued, a vital point in the journey was reached: hearers felt that they had no other alternative but to disclose their experiences, enabling them to seek professional help and support from others. Despite feeling ashamed, participants (10/20) reached the point of desperation whereby they needed to disclose negative feelings associated with voices. In some cases, talking about these experiences became paramount and facilitated discussions with others. For example, for P9 low self-worth, shame and helplessness reached a stage whereby voices no longer acted as a barrier to disclosure:

That's when I had to sort of tell them because I couldn't hold it in anymore, like I had to tell someone. Even though like you do feel like really ashamed and like beaten.

[P9]

Some participants were so intimidated by their voices that this became another barrier to disclosure. Yet, for P9, taking the risk of revealing her experiences when an opportunity arose was a chance she could not miss. In spite of her voice screaming threats, P9 too needed to scream for help:

[The voice] was shouting at me at this point. Sort of saying like "Shut up! Don't say anymore. What are you doing?" sort of thing. But, I just literally couldn't help it. I felt like I had that little doorway where I could suddenly start shouting out. Sort of telling people what was going on. [P9]

Over time, as resources to cope with voices became depleted, and voices' negative effect on self-worth and lifestyle could no longer be tolerated, participants were ready to seek help. For example, P4 was homeless, and tired of unemployment and the constant

battle with voices and their consequences for his life. Worn down, and in need of selfrespect, he had had enough and decided it was time to discuss his voices:

Why do you think you mentioned it then?

Just because I'd heard, had enough of, of liv-living with like the way I was living you know, homeless. Ob- you know obviously hearing voices and not able to hold down a job you know...

Why do you think changed, it, you started to react to them more?

Well, I've just got older and, and , and my, you know my mental, mental and physical resources aren't, aren't as power- powerful as strong as they used to be ... Just wanna put an end, just wanna put a, put an end, an end to t-to the to the insults you know. Just wanna ... I just wanna, just wanna have respect. [P4]

The monotony of living with voices on a daily basis, and the associated negative feelings, led to suicidal thoughts for some participants. Questioning what a life with voices meant resulted in desperation whereby disclosure or suicide were weighed against each other and considered as the only available options:

I just thought "There, there must be something better than waking up and feeling like this every day. Like, there must be. This, this can't be sort of it, really. Like this can't be what life is?" So I was just like "maybe I should [disclose voices]" I think it was like a final step really. I thought "You know what? I will see what happens. If it doesn't work out then I'll know, that if it doesn't work out, and therefore I'll think" I was thinking that I would end my life. [P14]

2. Effect of Disclosure on Others

In weighing up whether voices should be revealed, many interviewees considered the

potential impact of disclosure upon others: the needs of others ('Concerns about others') and the reactions of others (How will they respond?).

2.a. Concerns about Others

Some participants (5/20) worried that disclosure of voices would cause anguish to, and place a burden on, significant others in their lives. Consequently, revealing voices was not always a feasible option:

Did you tell anybody about it?

No!

Why not?

I wanted to help myself. I wanted to get rid of it myself instead of putting the burden on other people. [P12]

Most participants disclosed their voices to significant others such as parents or partners, but only after a period of time. However, P19's sense of responsibility to his family meant that they were entitled to know about his voices at onset:

I think I left it about an hour after it [voice onset] ... I sat upstairs by myself trying to make sense of things, trying to figure out what was going on. Then just decided: "No! Nothing's working." Sort of called my mum, my dad; went straight down the urgent treatment center at the hospital and got some, got seen...

Right! So very quickly you told everybody about it.

I, I figured especially my mum, my dad, my partner was out at the time but I did get hold of her and tell her. Especially they're, they're the most three important people to me so they're the people who need to know what's going on. [P19]

2.b. *How will they respond?*

Anticipation of how others may react affected most participants' (13/20) decisions to disclose. Other people's experiences, understanding and attitudes towards mental health issues functioned to either discourage or encourage participants' willingness to reveal and discuss their voices. In some cases, the decision not to disclose was bound within a history of family mental health issues and related stress. Awareness of these existing stressors influenced interviewees' reluctance to share their experiences, resulting in a belief that disclosure would add to family pressure and that voices needed to be managed alone:

As you got a bit older with your voice, why did you not tell anybody?

I really don't know ... I just thought like, well my dad, my sister's suffered with mental illness ... I knew that I didn't want to put any more pressure on my dad ... I think I felt a bit scared. I thought of my dad going through all that with my sister I didn't want to put any more pressure on him. So again it was that thing of not worrying anyone else, sort of deal with it on my own. [P18]

Alternatively, growing up within a family culture of mental health problems where voices were accepted and integrated within family norms meant that P15 was at ease discussing his experiences:

How were your family when you told them?

Yeah, they're f- we had family fully of, a fam- our family history full of people with mental illness. So my mum's mum heard voices. Her dad heard voices and I think her aunties heard voices. So it's not you know, they weren't too shocked. They were a little bit like "for God's sake here we go again." [P15]

However, believing that he would be judged negatively, P15 was not willing to talk

about voices with those who had not had similar experiences. He felt that other people who had not faced mental health issues would be prejudiced towards someone who experienced voices. Deeming himself vulnerable to their lack of understanding, P15 felt uncomfortable with exposing voice hearing to his friends:

Why do you not tell your friends?

'Cause I don't, I think they'd think I was barking [mad]. Yeah!

How do you think they would react?

Erm, not very well I don't think. No! [P15]

3. <u>Help-Seeking</u>

When they reached the point of wanting help from others, hearers needed to have someone to talk to. In a few cases (3/20), social circumstances influenced beliefs about the availability of others and whether disclosure was a viable option:

I never said anything 'cause I never had nobody to tell really. Like at what, and I was, a partner or anything like that. I wasn't close to my family. My mum and dad had just been divorced and it was just, there was so much going on I didn't feel I was able to talk to anybody at the time. [P16]

Help from others was not the norm for some participants, because of past experience and/or gender stereotypes. Despite struggling with his voices, P18 was uncomfortable sharing personal experiences. He had never been shown how to, or acquired the language to, express his feelings:

I just found it hard to deal with on my own but all my life I've sort of tried to deal with things on my own ... I know my dad's the same. He never, he never wants to sort of ask for help and I've never seen my dad ask for help so I don't know. It's like I never really spoke about anything as well because I never saw my dad, my brother or my granddad sort of show any

emotion. So I never saw them crying. I never saw anything. So I just thought "it's not a man" sort of, no "a male sort of thing to do." So I just kept it all in. [P18]

Even when wanting to seek help, the disorientation and fear that rose from their experiences with voices left some participants feeling confused and unable to determine who they could talk to or where they could get support:

I was a bit confused. Confused and frightened. I didn't know who to turn to.

[P14]

Discussion

Concerns about how talking about voices might affect the hearer and significant others influenced decisions to disclose. Hearers did not always acknowledge voices; if voices were acknowledged, struggles with voices were not always recognised. Some participants described a cognitive shift regarding disclosure; a process that moved from denial (barrier) to acceptance that voices were present and distressing (facilitator). If the perceived benefits of hearing voices (e.g., companionship) were considered to outweigh the perceived benefits of disclosure, then this transition was delayed. However, even if voices were acknowledged and help wanted, stigma often affected whether voices were revealed. The majority of participants reached a stage whereby beliefs concerning the adverse effects of disclosure were outweighed by the adverse effects of remaining silent.

The second higher order theme addressed the role that others play in disclosure. Participants' beliefs about the effect that revealing voices would have on family and friends influenced their decision. Voices were viewed from opposing perspectives: a liability that should not be shared; or something that, if remained undisclosed, was a betrayal to significant others. Experience of family and friends' attitudes towards

mental health also affected decisions: positive approaches encouraged disclosure whereas negative experiences evoked concerns and reluctance.

A third theme illustrated how seeking help could be complex and more than just a decision to disclose. Hearers were not always accustomed asking for support or confident that they could express their experiences. In addition, not everyone had a trusted other to confide in. How these themes relate to the disclosure of voices within this study can be seen in Figure 1 (online).

As in previous studies, participants were generally reluctant to disclose voices: delays in seeking help were associated with denial (McGlashan, 1999), misinterpretation of symptoms (Phillips et al., 1999) and fear of stigmatization (Compton et al., 2008). Our results partly concur with previous findings that fear of being judged negatively is related to not disclosing (Bay et al., 2016; Sickel et al., 2016). Alternatively, Bril-Barniv et al. (2017) found that, for some, mental health disclosure was a proactive decision, attributed to an effort in encouraging social change. Similarly, the present study showed that, in certain instances, the motivation to disclose centered upon confronting negative perceptions and exploring the meaning of voices with others. These differing approaches may reflect broader styles of recovery from psychosis: "integrators" seek to understand psychotic experiences and draw upon others' support, whereby those who "seal over" may reject the existence or severity of the illness (McGlashan, 1987).

Milligan et al. (2013) proposed a "Rejection" phase whereby voices are denied by the hearer as part of themselves. The present study expands upon this phase and suggests that, even if voices are accepted as part of the self, hearers may deny their negative effect, deny that their presence indicates a serious mental health issue, and reject that this needs to be addressed. Consistent with cognitive models of voices

(Morrison, 2001), the idiosyncratic nature of any rejection of voice hearing experiences was influenced by how hearers interpreted their experiences. Similarly, Milligan et al. (2013) discussed a period of "Crisis-induced Change," where a key negative event with voices results in either a positive or negative change. Although our findings partially concur with this theme, positive change (disclosure to others) was not due to a significant event but the cumulative effect of living with the distress of voices over time (c.f. de Jager et al., 2016).

Perceptions of others' reactions to disclosure were also influential. Boydell et al. (2006) found that young service users (with first episode psychosis or schizophrenia) often hid symptoms from family to avoid worry. Although several participants in our study echoed this point, those growing up in a social context where mental health issues were accepted found disclosure easier.

For some participants, disclosure of voices did not occur despite treatment for other mental health issues. This suggests that mental health stigma is hierarchical, with schizophrenia and psychosis symptoms carrying the most stigma. Whereas public awareness of depression, anxiety and eating disorders has improved, schizophrenia and hearing voices are often associated with danger, leaving hearers unwilling to discuss voices (Ruddle et al., 2011). Delays in disclosure raise questions as to why health professionals may not detect or discuss voices sooner. Health professionals can lack confidence to discuss voice hearing, and feel limited in their capability to adequately support hearers (Coffey and Hewitt, 2008).

The observation that hearers decided to disclose when the cost of non-disclosure was considered greater than the cost of disclosure corroborates theories of disclosure regarding stigmatized conditions (Greene, 2009; 2014). Reservations around voice disclosure and help-seeking may have long-term effects upon the progression of the

hearer's experience with voices. Disclosure models of stigmatized health conditions tend to focus upon post-diagnosis disclosure whereby first-disclosure has already occurred, but we examined voice hearers' decision-making processes prior to first-disclosure of a symptom. The present findings also suggest that, amongst some hearers, acceptance that voices are distressing and that support is required is an antecedent of the disclosure process. Consequently, our data offers insight into the processes of first disclosure among people who live with a stigmatized health condition. In addition, through focusing on a single symptom (hearing voices), this study adds to the literature on the disclosure of mental illness (Bril-Barniv et al., 2017).

Implications

The findings indicate a need to explore and challenge barriers to disclosure. There is also a need for strategies that focus on a) facilitating hearers to disclose voices at onset and b) encouraging positive responses from individuals who receive disclosure. As these issues operate within a multi-social context, we advocate a multi-dimensional approach targeting children and young people, the public, primary, secondary and tertiary care services.

Family involvement is key to facilitating pathways to care (Morgan et al., 2006), highlighting the need for education around initial symptoms of mental health issues and the necessity for early intervention (Boydell et al., 2006). We agree with Mueller et al. (2016) that educational programs encouraging a positive, informed and de-stigmatizing outlook towards mental health issues should be implemented in schools. The introduction of such a program at a time when children are beginning to comprehend rules of social desirability may help to reduce the stigma associated with hearing voices. An educated understanding of mental health problems from an early age could also enable young people to recognize symptoms of psychosis, encourage self-enquiry into

one's mental health, and support those distressed by voices to make informed choices about help-seeking.

If hearers feel confident of receiving a positive response from others, then they may be encouraged to disclose voices nearer to onset. The success of large scale campaigns aimed at de-stigmatizing mental illness is uncertain (Clement et al., 2013). An alternative approach is the "Headspace" model, which focuses on engaging young people with mental health services through integrated and coordinated specialist youth and carer-friendly services that address mental health, physical health, work/study, or substance misuse (Malla et al., 2016; McGorry et al., 2007). An online support service also allows young people to access professional help and advice (Malla et al., 2016; McGorry et al., 2007). The findings from this study suggest that public awareness of voice hearing could be promoted through a model similar to the Headspace model.

Because many people find it difficult to talk about symptoms of psychosis (Department of Health, 2012) it is essential that primary care practitioners feel confident discussing these experiences with patients. Evaluating the training needs of GPs may help to address uncertainties around detecting and discussing voices.

It is important that EIP practitioners recognize and are able to discuss service users' voice hearing experiences. Conventional approaches have typically discouraged enquiry into the experience of voice hearing, preferring to focus the hearer towards a more objective reality (Coffey and Hewitt, 2008). Enhancing therapeutic skills may build confidence and help practitioners to engage with clients distressed by voices. Coffey and Hewitt (2008) argue that mental health practitioners should be educated to deliver specific techniques for voice hearing such as supportive (validating patient's self-knowledge and responsibility) and catalytic (encouraging new self-understanding) interventions. Evidence suggests that brief Cognitive Behavioral Therapy for psychosis

(CBTp) delivered by experienced therapists can reduce the distress caused by the symptoms of psychosis (Hazell et al., 2016). The provision of training to deliver CBTp adapted to focus on voice hearing could help to build practitioner confidence in talking about voices, facilitate the identification and disclosure of such experiences, and help to meet the challenges faced by service users in accessing appropriate therapies.

Limitations

There are several limitations to the study. First, participants were recruited from a small, select sample of EIP service users, so findings might not be extrapolated to hearers who have not discussed voices with others. Research should explore the disclosure of voice hearing in more diverse groups of hearers (e.g. online data collection and hearing voices groups). Second, themes that were generated by the authors and interpretations of the data may be subject to personal preconceptions, but using multiple analysts mitigated this. Third, participant accounts of the period between voice onset and point of disclosure were retrospective, and may have been influenced by attenuated recall or current circumstances. Research should seek to recruit service users as near to voice onset as possible.

Conclusion

The processes of deciding to disclose voice hearing experiences and seek help are complex, with hearers considering the effect of disclosure upon themselves and significant others. In seeking to reduce the time between onset and treatment for distressing voices, interventions should seek to raise awareness and skill among people most likely to be the recipients of disclosure.

Acknowledgements

Dr Tina Perry-Moore, Dr Simon McCarthy Jones, Dr Georgie Paulik, Yvonne Awenat,

Leila Hughes, Kirsty Labuschagne, Charlotte Wilcox, Geoff Davies and the 'Voices over Time' study participants

Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

References

- Aleman A, and Larøi F (2008) *Hallucinations: The science of idiosyncratic perception*. Washington, DC: American Psychological Association.
- Baird J, Bell S, Brabban A, et al. (2012) IRIS Guidelines: Early Intervention in Psychosis IRIS Guidelines Update September 2012.
- Bay N, Bjørnestad J, Johannessen JO, et al. (2016) Obstacles to care in first-episode psychosis patients with a long duration of untreated psychosis. *Early intervention in psychiatry* 10(1): 71–76.
- Beavan V, Read J and Cartwright C (2011) The prevalence of voice-hearers in the general population: a literature review. *Journal of mental health (Abingdon, England)* 20(3): 281–292.
- Boyd T and Gumley A (2007) An experiential perspective on persecutory paranoia: A grounded theory construction. *Psychology and Psychotherapy: Theory, Research and Practice* 80(1): 1–22.
- Boydell KM, Gladstone BM and Volpe T (2006) Understanding help seeking delay in the prodrome to first episode psychosis: a secondary analysis of the perspectives of young people. *Psychiatric rehabilitation journal* 30(1): 54–60.
- Braun V and Clarke V (2006) Braun, V., Clarke, V. Using thematic analysis in psychology., 3:2 (2006), 77-101. *Qualitative Research in Psychology*, 3(2): 77–101.
- Bril-Barniv S, Moran GS, Naaman A, et al. (2017) A Qualitative Study Examining

 Experiences and Dilemmas in Concealment and Disclosure of People Living With

 Serious Mental Illness. *Qualitative Health Research* 27(4): 573–583.
- Byrne R and Morrison A.P (2010) Young people at risk of psychosis: a user-led exploration of interpersonal relationships and communication of psychological

- difficulties. Early Intervention in Psychiatry, 4(2): 162-168.
- Clement S, Lassman F, Barley E, et al. (2013) Mass media interventions for reducing mental health-related stigma. *The Cochrane database of systematic reviews* 7(7): CD009453.
- Coffey M and 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.
- Compton MT, Chien VH, Leiner AS, et al. (2008) Mode of onset of psychosis and family involvement in help-seeking as determinants of duration of untreated psychosis. *Social Psychiatry and Psychiatric Epidemiology* 43(12): 975–982.
- Danermark B, Ekström M, Jakobsen L, et al.(2002). Explaining society: Critical realism in the social sciences. Abingdon, UK: Routledge.
- De Jager A, Rhodes P, Beavan V, et al. (2016) Investigating the lived experience of recovery in people who hear voices. *Qualitative health research*, 26(10): 1409-1423.
- De Loore E, Gunther N, Drukker M, et al. (2011) Persistence and outcome of auditory hallucinations in adolescence: A longitudinal general population study of 1800 individuals. *Schizophrenia Research* 127(1–3): 252–256.
- Department of Health (2012) *Future in mind*. Available from:

 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414

 024/Childrens_Mental_Health.pdf.
- Greene K (2009) An integrated model of health disclosure decision-making. In: T. Afifi & W. Afifi (Eds) *Uncertainty, information management, and disclosure decisions:*Theories and applications, Oxford: Routledge, pp. 226–253.
- Greene K (2014) Disclosure of chronic illness varies by topic and target: the role of

- stigma and boundaries in willingness to disclose. In: Petrino S (ed.), *Balancing the* secrets of private disclosures, New York: Psychology Press, pp. 123–135.
- Gulliver A, Griffiths, KM and Christensen H (2010) Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC psychiatry*, *10*(1): 113.
- Hazell CM, Hayward M, Cavanagh K, et al. (2016) A systematic review and metaanalysis of low intensity CBT for psychosis. *Clinical Psychology Review*, 45: 183-192
- Malla A, Iyer S, McGorry P, et al. (2016) From early intervention in psychosis to youth mental health reform: a review of the evolution and transformation of mental health services for young people. *Social Psychiatry and Psychiatric Epidemiology*, 51(3): 319-326
- Mays N and Pope C (2000) Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, 320(7226): 50.
- McGlashan TH (1987) Recovery style from mental illness and long-term outcome. *Journal of nervous and mental diseass*, 175(11): 681-685
- McGlashan TH (1999) Duration of untreated psychosis in first-episode schizophrenia:

 Marker or determinant of course? *Biological Psychiatry*, 46(7): 899-907
- McGorry PD, Tanti C, Stokes R, et al. (2007) headspace: Australia's National Youth

 Mental Health Foundation-where young minds come first. *The Medical journal of*Australia 187(7): S68
- Milligan D, McCarthy-Jones S, Winthrop A, et al. (2013) Time changes everything? A qualitative investigation of the experience of auditory verbal hallucinations over time. *Psychosis* 5(2): 107–118.
- Morgan C, Abdul-Al R, Lappin JM, et al. (2006) Clinical and social determinants of

- duration of untreated psychosis in the AESOP first-episode psychosis study. *British Journal of Psychiatry*, 189(5): 446–52.
- Morrison AP (2001) The interpretation of intrusions in psychosis: an integrative cognitive approach to hallucinations and delusions. *Behavioural and Cognitive Psychotherapy*, 29(3): 257-276.
- Mueller J, Callanan MM and Greenwood K (2016) Communications to children about mental illness and their role in stigma development: an integrative review. *Journal of Mental Health* 25(1): 62-70.
- Padilla E, Molina J, Kamis D, et al. (2015) The efficacy of targeted health agents education to reduce the duration of untreated psychosis in a rural population. *Schizophrenia research*, *161*(2): 184-187.
- Penttila M, Jaaskelainen E, Hirvonen N, et al. (2014) Duration of untreated psychosis as predictor of long-term outcome in schizophrenia: systematic review and meta-analysis. *British Journal of Psychiatry* 205(2): 88–94.
- Phillips L, Yung AR, Hearn N, et al. (1999) Preventative mental health care: accessing the target population. *Australian and New Zealand journal of psychiatry* 33(6): 912–917.
- Romme M, Escher S, Dillon J, et al. (2009) Living with voices: 50 stories of recovery. Herefordshire: PCCS Books Ltd, p10
- Ruddle A, Mason O and Wykes T (2011) A review of hearing voices groups: Evidence and mechanisms of change. *Clinical Psychology Review*, 31(5): 757-766
- Sickel AE, Seacat JD and Nabors NA (2016) Mental health stigma: Impact on mental health treatment attitudes and physical health. *Journal of Health Psychology*, p.1359105316681430.
- Tracy SJ (2010) Qualitative quality: Eight "big-tent" criteria for excellent qualitative

- research. Qualitative inquiry, 16(10): 837-851.
- Vilhauer RP (2017) Stigma and need for care in individuals who hear voices.

 International Journal of Social Psychiatry, 63(1): 5-13.
- Yardley L (2000) Dilemmas in qualitative health research. *Psychology and health*, *15*(2): 215-228.
- Yung AR and McGorry PD (1996) The prodromal phase of first-episode psychosis: past and current conceptualizations. *Schizophrenia bulletin*, 22(2): 353-370.
- Yung AR, Killackey E, Hetrick SE, et al. (2007) The prevention of schizophrenia. *International review of psychiatry (Abingdon, England)* 19(6): 633–646.

Appendix: Figure 1

Figure 1. Disclosure of Voice Hearing

