

Full Title: Work-related experiences of people who hear voices: an occupational perspective.

Authors:

- 1) Lisa Craig, Occupational Therapist, Sussex Partnership NHS Foundation Trust.
- 2) Dr Josh Cameron, Principal Lecturer, School of Health Sciences, University of Brighton.
- 3) Dr Eleanor Longden, Postdoctoral Service-User Research Manager, Psychosis Research Unit, Greater Manchester West Mental Health NHS Foundation Trust.

Corresponding author:

Dr Josh Cameron
School of Health Sciences
University of Brighton
Robert Dodd Building
49 Darley Rd
Eastbourne
East Sussex
BN20 7UR
UK
j.cameron@brighton.ac.uk
+44 (0)1273 643648

Abstract

Introduction: Hearing distressing voices can be a significant mental health challenge, potentially disrupting working lives. Yet few studies have explored voice-hearing in relation to employment. This study aimed to understand the work-related experiences of voice-hearers, including the impacts on their working lives and their corresponding self-management strategies.

Method: A phenomenological approach gathered data from electronic diaries of five voice-hearers with experience of working. Data was analysed using thematic analysis.

Findings: Critical and distressing voices that demanded full attention were most disruptive of people's working lives, particularly affecting concentration, communication and task completion. At times voices were experienced as neutral and, for some, as supportive of work. Meaningful experiences of work could diminish the negative impact of voice-hearing. A range of resilience strategies were used to manage voices, notably: attempts to interact with voices and using activities (including work) to engage or distract them. The diary method of writing about one's experiences emerged as an unanticipated positive occupational coping strategy.

Conclusion: Practitioners should pay close attention to the diversity of individual voice-hearing experiences and self-management strategies (including occupational ones) and draw on these to support their clients' participation in work.

Keywords: self-management, auditory hallucinations, psychosis, work, resilience.

Work-related experiences of people who hear voices: an occupational perspective

Although typically associated with psychotic disorders, the phenomenon of hearing voices which others cannot hear is experienced by people with a range of psychiatric diagnoses as well as amongst non-patients (Sommer et al., 2010; Johns et al., 2014). Indeed, Beavan et al.'s (2011) systematic review of 17 surveys across nine countries established a median general population prevalence rate of 13.2%. It is likewise well-established that many people hear voices which have no negative impact on their lives (Sommer et al., 2010; Kapur et al., 2014). As such voice-hearing is increasingly framed within more psychological perspectives as opposed to the previous emphasis on models focused on psychotic diagnoses alone (The British Psychological Society, 2014; Longden et al., 2012; Upthegrove et al., 2016; Jones and Luhrmann, 2016). Nevertheless, despite these expanding frameworks for the aetiology of voice-hearing itself, it remains undisputed that many individuals experience their voices as distressing, with at times deleterious consequences (Woods et al., 2015).

Several studies have explored these negative impacts on people's daily lives. Notably, Kahlvold et al. (2013; 2014) have published two procedurally rigorous and reflexive qualitative studies examining how 14 psychiatric service-users experienced voice-hearing. Although voice characteristics varied, most participants heard angry or hurtful voices describing their lives as dominated by frequent voices which were difficult to manage. Hearing commanding voices demanding full attention were considered most disruptive, although voices experienced in the background still caused difficulties with concentration. Furthermore, voices were reported to disrupt sleep adding additional burdens to participants' lives.

Although healthcare professionals have a major role in supporting voice-hearers, research indicates dissatisfaction in how well this is always achieved (Romme et al., 2009). For example, in their qualitative study of community nurses' and voice-hearers' experiences, Coffey and Hewitt (2008) concluded healthcare providers frequently adopted approaches that were insufficient for meeting client needs; for instance, by emphasising medical treatment responses and having limited discussion about the influences of clients' past experiences on voice presence/content and/or the personal meanings that people attached to them. Similarly, Kapur et al.'s (2014) mixed methods study of young people (aged 11-29) and their parents found that many participants expressed dissatisfaction with the lack of normalising, holistic approaches to voice-hearing offered by mental health services. Taken together, this indicates an important research and practice potential for the type of occupational perspectives defined by Njelesani et al. (2014) as "a way of looking at or thinking about human doing"

(p226). However, notwithstanding this clear area of relevance, we were unable to identify any occupational therapy or occupational science related research specifically focused on the impact of voice-hearing on people's daily lives. In this respect, and in response to the numerous challenges that voice-hearers experience in combination with dissatisfaction for some aspects of statutory psychiatric care, survivor-led initiatives such as the Hearing Voices Network have been widely established aiming to support people to live more peacefully with their voices (e.g., by promoting such strategies as peer-support, coping enhancement, and disseminating psychosocial frameworks for understanding voice presence/content: (Escher and Romme, 2012; Longden et al., 2013).

Kalhovde et al.'s (2013; 2014) studies included a few examples of how voices disrupted work (for instance, requiring one participant to leave a meeting in response to a voice demand) but these were set in the context of impacts on daily life in general. They also noted most participants had left work/study by the time of interview, though the 2014 article reported many had not lost hope in the possibility of working. In a large qualitative study, Koletsi et al. (2009) explored vocational support experiences of participants diagnosed with psychosis finding that half the participants reported psychotic experiences as problematic in retaining work. There was likewise limited specific attention to voice-hearing, though one example was that voices could adversely affect concentration at work. Nithsdale et al.'s (2008) smaller qualitative study concluded that, in contrast to previous research which they cited, challenges of coping with experiences such as voice-hearing were of a greater concern to participants than stigma and discrimination. They found a lack of managerial support was commonly reported, with employment loss attributed to unsupportive workplaces as well as an inability to cope with mental health difficulties.

To our knowledge there is currently no research which solely focuses on the impact of voice-hearing on people's working lives. This is a significant gap, given the emphasis placed on the role of work in recovery-orientated literature (Bond and Drake, 2014) as well as in occupational therapy mental health vocational research (Blank et al., 2015; Cameron et al., 2016; Arbesman and Logsdon, 2011). Indeed, Nithsdale et al. (2008) identified a need for more research into the impact of psychosis symptoms on work; a point echoed by Upthegrove et al. (2016) who express concern that without studies focusing on the daily realities of living with voices, the increasingly diverse theoretical models for understanding voice-hearing will have only limited relevance to people's actual lives. Woods et al.'s (2015) large scale phenomenological survey of voice-hearer's experiences has gone some way to addressing this concern, but it also focuses on internal experiences of hearing voices (e.g., voice characteristics) rather than impacts of voices on activities of daily living such as work.

The current study addresses this gap by reporting lived experiences of the diverse effects that voice-hearing can have on working lives. Whilst the recruitment method, in line with practice concerns, involved a focus on more negative experiences, the possibility of neutral and positive experiences were not ruled out. A further aim was to understand what strategies people used to manage negative impacts in the hope that this will be helpful to individuals facing similar challenges and those supporting them.

Method

Approach

A phenomenological approach (Smith, 2007) within an interpretivist paradigm (Willis, 2007) was adopted. This seeks to understand the nature of reality and holds that phenomena are experienced subjectively. Accordingly, this research explored multiple meanings and interpretations of people's occupational lives, where truth is understood to be 'relative' to the individual.

Researcher characteristics

Qualitative research recognises that personal and contextual researcher characteristics can influence and potentially enrich research (Gough, 2003). Correspondingly, the researchers' interest in voice-hearing is influenced by social psychiatry (Escher and Romme, 2012) and practice experience in occupational therapy.

Participants

Five participants were recruited using purposeful sampling via a voice-hearing support website whose host agreed to post an advertisement for the study following an email request from the first author. This enabled recruitment of people likely to have experienced some challenges associated with voice-hearing; however it did not eliminate the possibility of some positive experiences, nor did it limit participation by diagnostic criteria. Inclusion criteria were adults (aged 18 – 65) who reported that they heard voices regularly, had work experience, and were not hospitalised.

Procedure

Data were gathered through electronic diaries written by participants. Woll (2013) has provided an evidence based justification for the use of diary writing as a method in phenomenological; research. This method has been argued to have advantages over face-to-face interviews by allowing time to reflect upon responses, reduced cost to researcher and participant, encouraging more open disclosure, and enabling the participation of people from a dispersed geographical area and/or with certain disabilities (O'Conner et al., 2008; Woll, 2013; Markham, 2004). To support diary writing, participants were sent the guidance presented in Figure 1. This was developed by advice from a researcher with lived experience of voice-hearing. Participants emailed individual diary entries on between three to six occasions during data collection, allowing the researcher to pose follow-up questions and ask for clarifications when needed. Ethical permission for the study was obtained from the University ethics committee and all participants provided written informed consent.

Figure 1. Guidance notes to focus participants' writing.

I am interested in your **day to day** experience of working (work can be paid or voluntary, please say which). What is it like to work and hear voices? You can write as often as you like, daily, weekly or whatever suits you.

Here is some guidance, this might help focus your writing.

Please describe how you got your job, what your job involves and the responsibilities you have.

Please write about your **everyday** experience of hearing voices at work.

Research suggests that there are positive and negative things about working. What do you think?

Please include these experiences in your writing.

Are you interested in what you do at work? Do you think this influences how you hear voices?

Please include this in your writing.

Do you think it is important to be interested in what you do at work? Please write about this.

Research suggests that some people develop ways of managing hearing voices at work. Some people find it difficult. Please write about your experiences.

Some people choose to tell their employer or someone at work about hearing voices. Some people choose not to. Please write about your experience.

Some people have support from employment services to sort things out at work. If you have experience of this please write about it.

When you are writing, if you can, please include what the voices say and if they are quiet or loud, how often they talk to you. If possible please describe how this makes you feel. Did the voices encourage you or make it difficult for you to do the things you needed to do at work? Don't worry about language here. Whatever you hear, it's OK to write it down.

If you can think of anything else that you think would be helpful for other people to understand about your work-related experiences please write about this.

Data analysis

Data analysis followed the principles of thematic analysis (Braun and Clarke, 2006). This followed a predominantly inductive approach that involved identifying semantic (i.e., more explicitly apparent) themes in the data supported by researcher interpretation. Diaries were read and reread until familiarity with the data was obtained after which initial emergent codes were identified and then collated into potential themes. Themes were reviewed by the first and second author to determine how they worked in relation to each other and the whole data set, resulting in a thematic map of the

data. Themes were then 'defined and refined' before selecting compelling verbatim comments to evidence the findings.

Credibility

Reflexivity was supported by the first author writing a research journal. Member checking strategies ensured participants' accounts were accurately understood, enhancing credibility. Regular input and advice was also sought from people with both lived experience of voice-hearing and relevant research expertise.

Findings

Nine voice-hearers expressed interest in the study and received information and consent forms. Two people did not return consent, one declined to participate, and the fourth consented but not did not return any data. The five remaining participants submitted electronic diary entries over a period of between ten days to three weeks. All names are pseudonyms. Participant characteristics are reported in Table 1.

Table 1. Participant characteristics

Pseudo- nym, age, gender	Highest education and work	Duration and current frequency of voice-hearing	Voice characteristics	Reported diagnosis
Linde, 31, Female	Bachelors degree Currently working full time in private sector	Since childhood Every day for most of the day	Location: inside the head Voice 1: older than Linde, male, always aggressive and commanding Voice 2: also older than Linde, female, switches between being nice and encouraging to angry and threatening Voice 3: female child who screams "STOP" Voice 4: older female child who screams "AHHH" Other voices: background voices "like a tea party". Other sounds: church bells and music	None reported

Alice, 55, Female	Postgraduate diplomas Used to work full time in the public sector	Nine years All the time	Location: external, through the ears Voice 1: unrecognised male Voice 2: unrecognised male Both voices provide a commentary on what Alice is doing. Also abusive, derogatory and commanding Other voices: The Crowd, like a football crowd, mainly words that don't make sense Other experiences: Alice also has visions and unusual beliefs	Paranoid schizophre nia
Katy, 24, Female	Further education Self employed	18 years All the time	Location: inside the head Voice 1: male, about 28 years old, present for 18 years, caring, funny, loving, fiercely protective and possessive Voice 2: male, early 30s, present for 4 months, polite, calm, quick to rebuke, can be self-centred and mean Both voices can be unkind, although they can also be encouraging and caring, particularly Voice 1	Schizophr enia

Amelia, 43, Female	Doctorate Used to work full time in private (service) sector	30 years Almost all the time	Location: inside the head Voice 1 and voice 2 : not identified as male or female, extremely loud, not always clear. They comment on Amelia's actions and give commands. They are critical, judgemental and abusive, terrorizing and scary	Schizoaffective disorder
Sarah, 61, Female	Masters degree Self employed	56 years Sometimes	Location: inside the head Multiple voices : mostly androgynous, it is more of a whole-body experience rather than just auditory. Some critical and blaming and some reassuring. Sarah has recently been framing the voices' intent in a strengths-based manner, as reassuring, helpful and compassionate.	None reported

Analysis revealed four main themes which are displayed with sub-themes in Table 2. Analysis identified that all participants reported data that endorsed these themes and sub-themes.

Table 2. Themes and subthemes

Theme	Subthemes
1 Interactions between voices and work	Impact of voices on work Impact of work on voices
2 Managing voice-hearing at work	None identified
3 Voice-hearing and everyday occupations alongside work	None identified
4 Hiding and disclosing voice-hearing with others	None identified

Interactions between voices and work

Analysis revealed that participants' voices and occupational responsibilities impacted on one another in various reciprocal ways.

Impact of voices on work

Four participants described how hearing voices competed with work for their attention in ways that made working life challenging. In turn, how people experienced their voices influenced impacts on work. Three participants, described how voice-hearing involved a running commentary on their actions, either telling them what to do or as conversations with or about them. This was often interchangeable and unpredictable.

While it was often possible to do routine work whilst voices provided a running commentary, work requiring high levels of concentration was more challenging:

...I was hearing the two main voices carry on with their running commentary on what I was doing. This made it difficult to concentrate and focus on what I was doing...the voices took a different tack.
[...]

[Voice 1] – 'She's dying – look – look –she's dying!'

[Voice 2] – 'It's her fault – Bitch – Fault – Her'

[...]

[Voice 1 and Voice 2] – ‘They know it’s her fault – everyone knows.’ (Alice).

Participants reported experiencing voices loudly in the foreground or quietly in the background. Most reported that distressing foreground voices impacted negatively on work, making it difficult to think, interact with clients and colleagues, complete tasks and/or meet deadlines. In turn, participants reported difficulties concentrating, processing and synthesising information:

Voices one and two were at the foreground shouting at me that I wasn’t good enough for this world, that I couldn’t do the job, I was a whore etc. At work it was difficult, that day I had to think a lot about difficult cases [...] It is hard to think and hard to concentrate. (Linde)

The extent to which voice-hearing distracted participants from work varied. For some, it stopped them working:

Work was a distraction but the voices were a bigger distraction. (Alice).

Critical and distracting voices created situations which could exacerbate existing work difficulties. For example, voices’ interference could cause participants to doubt their decisions and actions, resulting in checking and repeating tasks leading to longer working hours.

However, there were also instances when participants described voices being helpful at work, such as providing advice and reminders:

[...] like ‘what’s the status of this task’ or ‘don’t you forget your appointment this afternoon’ and ‘you have to drink something’.” (Linde).

Others described how trusting voices could result in positive outcomes. For example, one participant reported that without the voices she would not have achieved financial stability, as she drew upon her voices’ input to enhance her role as health and well-being practitioner.

Impact of work on voices

For some participants, meaningful work activities had a positive impact on voice-hearing experiences. Work was important to most participants, who described their jobs passionately and as something they missed when they had no work. A diversity of tasks, people and places was described as beneficial:

I find the variety in clients and tasks very nice. As to my voices, they were alternating between the foreground and the background, but they weren’t aggressive or disturbing most of the time. Especially when I was at work I could cope very well with them and they didn’t distract me. (Linde)..

Many participants likewise referred to work as providing a distraction from their voices. For example, being busy was associated with quieter background voice-hearing:

The busier I am the quieter they get. Most of the time. (Katy).

Some participants also identified specific physical, social and institutional environmental factors that influenced voice-hearing, including: noise, temperature, being alone or with others, and workplace attitudes. Thus, Linde described how working from home did not sufficiently distract her from voices, so she preferred going to her workplace:

When I was at home, I couldn't cope with it very well [...] There was no distraction anymore, I was alone and I couldn't push the voices to background anymore, so they stepped up again. (Linde).

However, work-related stress also impacted negatively on voice-hearing, particularly for two participants whose roles involved responsibility for others' wellbeing. Nevertheless, for most participants benefits of working outweighed negative factors:

How could being positive, liking what you do, creating value and feeling valued, earning a decent income, being able to help others and myself be a "bad" thing?" (Sarah).

Managing voice-hearing at work

Various strategies were used to self-manage voice-hearing, including: listening, talking back, bargaining with and ignoring voices, practical self-help strategies such as mindfulness practice, and managing voices through performing occupations. Deciding how to respond to voices was difficult for many, as a strategy used effectively one time was not always successful. For some, listening to voices helped concentration; however, for others, talking back and/or ignoring them was more effective. In turn, it was apparent that attempts to ignore voices had varied consequences depending on voice characteristics and content, work demands, and participants' mood at the time. For example, one participant described how ignoring her voice could be physically painful:

... ignoring Voice 1 for too long is not a good idea. He can cause severe pain in my head or ears, like a ringing sound that's too loud. (Katy).

Bargaining with voices was adopted as a strategy by many participants and which, when successful, helped to quieten them:

Whilst driving to work in my car I would say ' OK I promise if you leave me alone today I will listen to you both tonight when I'm at home'. " (Alice).

Other self-help strategies included mindfulness, focusing on and writing down what colleagues or customers say, talking tasks through in one's head, working at one's own pace, sleep, self-made coping cards, and recovery action plans. Some participants engaged in specific activities to manage their voices, including: listening to music or radio, watching television, reading, and playing games. In this respect, attending to the interests of voices (such as listening to a voice's preferred music) could be particularly beneficial. For example, Katy reported that when voices 'joined in' activities, they were often quieter:

Gaming is fun, we all seem to enjoy it, Voice 1 likes puzzle games and Voice 2 likes bloody shooting and scary games. Good for the heart according to him. A happy Voice 2 is a quieter Voice 2. (Katy).

Some participants took medication, although this did not automatically stop or reduce voice-hearing and was generally used alongside other coping strategies:

Tried to proceed with my day after documenting my experience. Took my AM meds. Turned on the radio while in the shower for multiple sensory inputs. (Amelia).

Finally, the process of reflecting on and writing about their experiences of voice-hearing at work was reported by all but one participant as an unanticipated positive outcome from participating in the research:

[Writing the diary] helped me (and my therapist) to get more insight into my voices, the behavior of the voices and my coping strategies. Thank you for making that possible, your questions were very helpful with that, it really made me think about the voices!" (Linde).

Voice-hearing and everyday occupations alongside work

In addition to their immediate working roles, participants described how voice-hearing could interfere with numerous activities of daily living, such as plans for work, travelling to work, and leisure:

Doing household chores while watching TV/listening to music. [Voice 1] ... 'Your life is worthless. You should die. You should kill yourself – or I will'. (Amelia).

Participants described how hearing voices could be physically, mentally and emotionally tiring yet could also interfere with sleep. Voices were present when falling asleep, dreaming and on waking, and on occasions woke participants up – although for some, falling asleep whilst hearing voices was not problematic and could be a means of coping. However, lack of sleep was associated with increased voice activity and coping with voices became more challenging when tired. No sleep or too much sleep likewise impacted negatively on everyday life including work:

Trying to fall asleep [...] [Voice 1] 'Why are you trying so hard to help yourself? Don't you know that you'll fail, that you're hopeless?' (Amelia).

Hiding and disclosing voice-hearing with others

All participants found it difficult to conceal the fact they heard voices, with Sarah reporting that "Fitting in" was harder than living with the voices. Sometimes it was not possible to hide voice-hearing experiences, leading to colleagues commenting on behaviour:

Once I was talking to my voices when a colleague walked into the office. After this happened I always went into the disabled toilets to talk to my voices. (Alice).

Discussions with co-workers about voice-hearing varied. This included experiences of stigma and fear, not being understood, and concerns about consequences of disclosure. Thus, disclosing voice-

hearing at work was generally not recommended by participants, although for Sarah this was tempered with an acknowledgement of the likelihood that other people at work may also hear voices:

I recommend against telling workers. They get too curious, stereotype, and avoid. Short careers result. I am not advocating hiding, I am advocating recognizing that of any twenty workers in your workplace, at least one and probably more have the same profound experience of communication. (Sarah).

So, despite her reticence, Sarah identified with the principle of disclosure by describing voice-hearing as part of who she is; and that to learn to live with it, she needed to “come out” likening it to disclosing sexuality. However, others had not shared their experiences due to a fear of being considered “crazy” and unfit to work. In this regard, stigma inside the workplace was a challenge. Alice described telling no one for some time, including health professionals, due to fears of being diagnosed with schizophrenia. She stated that while disclosures about her mental health were required to return to work, in hindsight she considered it to have caused additional difficulties:

I told my manager I heard voices at a return-to-work interview. I think this was a mistake because at every subsequent review by my manager I was asked if I was hearing voices. I think they used this as a barometer of my mental health. (Alice).

Disclosure led to a role change and retraining programme which Alice experienced as supportive. However, the feeling of being scrutinised increased her experiences of more negative and challenging voices.

Some participants using mental health services reported a disparity in how professionals understood and responded to voice-hearing. For Katy, it felt that professionals did not take her experiences seriously in the sense that “voices don’t exist” unless excessively distressing or commanding:

They want to cure it, I don’t. [...] They simply don’t understand, if they’re not horrible and trying to make me commit suicide then they’re not there. (Katy).

Others wrote about telling significant others, mostly close family and friends, although invariably felt they were not understood which prompted feelings of loneliness. However, with support, one participant was able to disclose publicly and emphasise the positive aspects of voice-hearing, which in turn positively influenced her wellbeing and working life.

Discussion

Analysis revealed how hearing voices and work were experienced as competing distractions. Voice phenomenology was diverse within and across individuals in a way consistent with the more broadly focused research by Woods et al. (2015). Our findings also provide new insights into ways individuals experience and manage voice-hearing in the workplace.

Voices and work: competing distractions

Participants' working lives were dominated by the competing distractions of job demands and voice-hearing. Most found hearing voices and working to be challenging, which is consistent with Nithsdale et al.'s (2008) research into the impact on work of psychotic symptoms more generally. Our results also correspond with Koletsi et al.'s (2009) finding that impaired concentration is a prime mechanism through which voice-hearing can adversely affect work performance. We found this to be particularly the case with regard to more complex tasks when distressing voices were heard in the foreground, which in turn accords with Kalhovde et al.'s (2013; 2014) findings about the impact of voices on daily life more generally. Problems with social interaction and fatigue were also in line with difficulties reported by Kalhovde et al.'s (2014) participants, although the current findings additionally suggest that, in partial consequence of these problems, voice-hearing can substantially interfere with people's ability to complete work tasks and meet deadlines. However, our study also provided insight into instances when voice-hearing helped participants to work. Thus, in a finding not highlighted in the reviewed literature, a number of people revealed hearing neutral and positive voices which could help reassure and advise at work. Acknowledging and building on this occupational strength may contribute to addressing challenges in other areas.

Kalhovde et al. (2014) recognised the importance of the relationship between work and voice-hearing, suggesting engagement in meaningful and productive activity can reduce voice intensity and help distract the hearer. Similarly, participants in the current study described how being engaged in varied and meaningful work activities could quieten voices, suggesting that occupational engagement has a direct impact on voice-hearing. Thus, with a slightly different emphasis from Kalhovde et al.'s (2014) study, it seems the therapeutic effect of occupational engagement did not just improve participants' ability to *ignore* voices but could change how voices were *experienced*; i.e., as quieter and/or more cooperative.

The current findings are consistent with research suggesting background voice-hearing makes daily life harder, whereas commanding foreground voices cause significant disruption, often resulting in work absence (Kalhovde et al., 2014). In turn, the findings expand on how voices may interfere with sleep, leisure, and other activities of daily living. In this respect, and consistent with research about the disruptive impact of voice-hearing on sleep (Waite et al., 2016), we found that lack of sleep resulted in short irregular absences from work, as well as negatively influencing mood, voice-hearing intensity, and occupational functioning.

Analysis indicated variation in the extent to which engagement in work influenced voice-hearing. This appeared to be related to interest in work, variety, amount of work, and the workplace environment. For some participants, working at home did not provide the same 'distraction' or therapeutic benefit as an external workplace. This highlights the importance of attending to the occupational context of work, especially in light of Wilcock and Hocking's (2015) concern that such dimensions are often overlooked. Similarly, research has identified that work and co-workers can be perceived as sources of stress as well as support to people with mental health difficulties (Koletsi et al., 2009; Cameron et al., 2016); and this study supports both findings, in that while most participants perceived work as

beneficial, for some it could be "toxic" - a source of stigma and stress, which in turn induced distressing voices.

Managing and living with voice-hearing at work: an occupational perspective

Nithsdale et al. (2008) suggested that participants experiencing psychosis may often use avoidant coping methods, including overworking, which consequently exacerbate mental health problems. However, in our study overworking seemed to occur less as an avoidant coping strategy but rather as a consequence of people seeking to complete tasks that had been disrupted by voices. Despite adopting self-management strategies, two participants reported that they had eventually stopped working in the past due to distressing voices. However, there were also many examples of participants coping positively and proactively with their experiences. The fact that voice-hearing phenomenology varied between and within individuals is a logical explanation for the similarly diverse range of coping strategies adopted to manage voices. However, within this diversity some shared features still emerged.

Consistent with broader mental health vocational research (Cameron et al., 2016; Blank et al., 2015; Nithsdale et al., 2008) our findings indicate that most participants engaged in numerous meaningful and creative strategies to manage voice-hearing inside and outside of work. Many of these, such as reading or listening to music, typify what Wright et al. (2007) characterised as 'positive distraction'. This is one of four types of 'flow' experience; activity which demands little skill or engagement, is associated with pleasure, and has short-term effects. However, for our participants the short-term effects could be significant in terms of deferring experiences of disturbing voices and thus enabling occupational tasks to be performed.

At a more potentially more meaningful level than positive distraction, analysis also indicated that the process of diary-keeping helped increase participants' awareness and understanding of work-related voice-hearing experiences. The research methodology thus emerged as an effective occupational strategy that had not been anticipated by either researchers or participants. Expressive and creative writing was also found to be helpful in Kalhovde et al.'s (2014) study. It may be that by writing about their voices, participants were helped to understand more about the relationship dynamics they had with them. In turn, this supports both qualitative (Hayward et al., 2015) and quantitative (Stainsby et al., 2010) research around the value of therapeutic approaches which help people to better understand emotional and relational dynamics of their voices as well as endorsing previous studies that highlight limitations, at least for some voice-hearers, of being encouraged to always ignore their voices (Coffey and Hewitt, 2008; Kapur et al., 2014). However, it should also be noted that for our participants, criticisms of mental health services' vocational support was not so much that workers did not take their voice-hearing experiences seriously, but rather that there was an assumption that all voices were negative and that professionals exhibited a desire to "cure" people of voice-hearing.

Mobilising occupational capital to support a resilient response to challenges

In their vocational mental health study Cameron et al. (2016) proposed a new concept of occupational capital defined as “a combination of accessible external opportunities and supports for occupational participation and internal capacities and skills to access this” (p281). This concept closely corresponds to participant endeavours in our study, who sought to use internal skills and capabilities through numerous self-help and occupational strategies in order to access available sources of external opportunities and supports. Where they were able to do this they demonstrated a resilient response to challenges they faced. In turn, this resilience can be understood not as an exclusively internal individual characteristic, but also in ecological terms encompassing person, occupation and environmental factors inside and outside of the workplace (Cameron et al., 2014). Analysis suggests this is a dynamic process requiring voice-hearers, co-workers, managers and health professionals to constantly appraise how to respond to voice-hearing. Our study highlights the effort required when demands on concentration are already high. This is potentially an important area to address in work-related intervention planning with voice-hearers, co-workers and managers.

Limitations

These results should be considered in view of study limitations. Firstly, findings from this exploratory research have been co-constructed between participants and researchers within specific temporal and contextual parameters; thus we acknowledge others may interpret the data differently. Secondly, while the diary writing strategy offered several methodological advantages, it also risked loss of some spontaneous responses that may have been provided using a more direct method such as interviewing. The research design additionally relied on internet access which, although increasing access for some individuals, may have restricted participation opportunities for others. The small-scale qualitative design and in some respects homogeneous participant characteristics (e.g., all female and relatively highly qualified) also limits the generalisability of the findings in terms of informing theory and possible future research and practice applications. Finally, while not all participants reported psychiatric service use, recruiting via a voice-hearing support website made it more likely that people with at least some negative experiences of voice-hearing participated which may have under-estimated the potentially positive impact of voice-hearing on work.

Implications for practice

The complex and variable impacts of voice-hearing at work highlighted within this study may help occupational therapists and other vocational and mental health practitioners offer clients more effective and individualised support. This includes avoiding the assumption that voice-hearing has a uniformly negative impact. In turn, understanding how different features of voice-hearing affects occupational functioning may help to highlight the challenges faced by voice-hearers at work and inform interventions. Such supports need to consider the worker, the nature of their work and workplace and, given the reported challenges of stigma and disclosure, the attitudes of colleagues. The second author has been able to apply these ecological vocational principles, which do not

assume voices to have an unequivocally negative impact, to a mental health recovery college course session focused on resilience at work that is part of a wider applied research project.

Study limitations highlight the need for more research into interactions between voice-hearing and work with a broader range of participants. More specifically, in light of unanticipated reports of the positive impact of the research methodology, future studies could explore whether 'voice and doing' diaries can enhance understanding of the relationship between voice-hearing and 'doing' at work; and, in turn, how this could be operationalised into positive occupational impacts.

Conclusion

This study has contributed novel data on the impact of hearing voices on working lives. It has found that people who hear voices experience a diverse range of impacts at work ranging from positive to neutral to negative. Participants deployed a range of self-help and occupational strategies to manage negative impacts. In order to best support clients whose voices can at times have a negative effect at work, occupational therapists should be open to listening to the breadth of experiences within and across individuals and support people to identify and share resilience strategies. In turn, we suggest that this can be accomplished most effectively using a holistic framework that considers the interactive dynamics between the person, their occupations, and environment.

Word count: 5073

Key messages

Key findings

- Voice-hearing has a diverse impact on individuals' occupational lives that can be positive as well as negative and neutral.
- Writing diaries can promote a better understanding of one's voice-hearing experiences and help identify work-related coping strategies.

What the study has added

This is the first qualitative study to focus on the specific impact of voice-hearing on people's working lives. It highlights the diversity of these experiences and draws attention to helpful strategies for managing voice-hearing in the workplace.

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Research ethics

This research received approval from the University of Brighton, Health and Social Science, Science and Engineering Research Ethics and Governance Committee (7.4.2015).

Declaration of conflicting interest

The authors confirm that there is no conflict of interest.

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References

- Arbesman M and Logsdon DW. (2011) Occupational therapy interventions for employment and education for adults with serious mental illness: a systematic review. *American Journal of Occupational Therapy* 65: 238-246.
- Beavan V, Read J and Cartwright C. (2011) The prevalence of voice-hearers in the general population: A literature review. *Journal of Mental Health* 20: 281-292.
- Blank AA, Harries P and Reynolds F. (2015) 'Without occupation you don't exist': Occupational engagement and mental illness. *Journal of Occupational Science* 22: 197-209.
- Bond GR and Drake RE. (2014) Making the case for IPS supported employment. *Administration and policy in mental health and mental health services research* 41: 69-73.
- Braun V and Clarke V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77-101.
- Cameron J, Hart A and Sadlo G. (2014) Resilience at work. In: Ionescu S, Tomita M and Cace S (eds) *The Second World Congress on Resilience: From person to society. Conference Proceedings*. Bologna: Medimond, 961-966.
- Cameron J, Sadlo G, Hart A, et al. (2016) Return-to-work support for employees with mental health problems: Identifying and responding to key challenges of sick leave. *British Journal of Occupational Therapy* 79: 275-283.
- 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: 1591-1600.
- Escher S and Romme M. (2012) The hearing voices movement. In: Blom JD and Sommer IEC (eds) *Hallucinations*. New York: Springer Verlag, 385-393.
- Gough B. (2003) Deconstructing reflexivity. In: Finlay L and Gough B (eds) *Reflexivity: a practical guide for researchers in health and social care*. Oxford: Blackwell Science, 21-35.
- Hayward M, Awenat Y, McCarthy Jones S, et al. (2015) Beyond beliefs: A qualitative study of people's opinions about their changing relations with their voices. *Psychosis* 7: 97-107.
- Johns LC, Kompus K, Connell M, et al. (2014) Auditory verbal hallucinations in persons with and without a need for care. *Schizophrenia Bulletin* 40: S255-S264.
- Jones N and Luhrmann TM. (2016) Beyond the sensory: Findings from an in-depth analysis of the phenomenology of "auditory hallucinations" in schizophrenia. *Psychosis: Psychological Social And Integrative Approaches* 8: 191-202.
- Kalhovde AM, Elstad I and Talseth A-G. (2013) Understanding the experiences of hearing voices and sounds others do not hear. *Qualitative Health Research* 23: 1470-1480.
- Kalhovde AM, Elstad I and Talseth A-G. (2014) "Sometimes I walk and walk, hoping to get some peace." Dealing with hearing voices and sounds nobody else hears. *International Journal of Qualitative Studies on Health and Well-being* 9: 23069 - <http://dx.doi.org/10.3402/qhw.v9.23069>

- Kapur P, Hayes D, Waddingham R, et al. (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: 527.
- Koletsis M, Niersman A, van Busschbach JT, et al. (2009) Working with mental health problems: clients' experiences of IPS, vocational rehabilitation and employment. *Social Psychiatry and Psychiatric Epidemiology* 44: 961-970.
- Longden E, Corstens D and Dillon J. (2013) Recovery, discovery and revolution: the work of Intervoice and the hearing voices movement. In: Coles S, Keenan S and Diamond B (eds) *Madness contested: Power and practice*. Ross-on-Wye: PCCS Books, 161-180.
- Longden E, Madill A and Waterman MG. (2012) Dissociation, trauma, and the role of lived experience: toward a new conceptualization of voice hearing. *Psychological Bulletin* 138: 28-76.
- Markham A. (2004) Internet communication as a tool for qualitative research. In: Silverman D (ed) *Qualitative research –theory, method and practice*. 2nd ed. London: SAGE, 95-124.
- Nithsdale V, Davies J and Croucher P. (2008) Psychosis and the experience of employment. *Journal of Occupational Rehabilitation* 18: 175-182.
- Njelesani J, Tang A, Jonsson H, et al. (2014) Articulating an Occupational Perspective. *Journal of Occupational Science* 21: 226-235.
- O'Conner H, Madge C, Shaw R, et al. (2008) Internet-based interviewing. In: Blank G, Lee RM and Fielding N (eds) *The SAGE handbook of online research methods*. London: SAGE, 271-289.
- Romme MAJ, Escher S, Dillon J, et al. (2009) *Living with voices: 50 stories of recovery*, Monmouth: PCCS Books in association with Birmingham City University.
- Smith JA. (2007) *Qualitative psychology: a practical guide to research methods*, London: SAGE.
- Sommer IEC, Daalman K, Rietkerk T, et al. (2010) Healthy individuals with auditory verbal hallucinations; who are they? Psychiatric assessments of a selected sample of 103 subjects. *Schizophrenia Bulletin* 36: 633-641.
- Stainsby M, Sapochnik M, Bledin K, et al. (2010) Are attitudes and beliefs about symptoms more important than symptom severity in recovery from psychosis? *Psychosis: Psychological, Social and Integrative Approaches* 2: 41-49.
- The British Psychological Society. (2014) *Understanding psychosis and schizophrenia. Why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help*. Leicester: The British Psychological Society Division of Clinical Psychology.
- Upthegrove R, Broome MR, Caldwell K, et al. (2016) Understanding auditory verbal hallucinations: a systematic review of current evidence. *Acta Psychiatrica Scandinavica* 133: 352-367.
- Waite F, Myers E, Harvey AG, et al. (2016) Treating Sleep Problems in Patients with Schizophrenia. *Behavioural and Cognitive Psychotherapy* 44: 273-287.
- Wilcock AA and Hocking C. (2015) *An occupational perspective of health*, Thorofare: SLACK.
- Willis J. (2007) *Foundations of qualitative research: interpretive and critical approaches*, London: SAGE.
- Woll H. (2013) Process diary as methodological approach in longitudinal phenomenological research. *Indo - Pacific Journal of Phenomenology* 13: 1-11.
- Woods A, Jones N, Alderson-Day B, et al. (2015) Experiences of hearing voices: analysis of a novel phenomenological survey. *Lancet Psychiatry* 2: 323-331.
- Wright JJ, Sadlo G and Stew G. (2007) Further explorations into the conundrum of flow process. *Journal of Occupational Science* 14: 136-144.