

Hearing Voices

*The Histories, Causes and Meanings
of Auditory Verbal Hallucinations*

Simon McCarthy-Jones



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5 The lived experience of hearing voices in individuals diagnosed with a psychotic disorder: or, the journey from patient to non-patient

In Chapter 4 we established what voices are like in people who have received psychiatric diagnoses. This tells us nothing about what it is like for these individuals to live with voices, though, and we may rightly ask what their lived experience of hearing voices is actually like. In the first half of this chapter we will draw on the peer-reviewed qualitative literature in this area. This will show that loss and recovery of basic human needs are fundamental themes reported by voice-hearers who have entered and then emerged from patienthood. The second part of the chapter will then focus on the more radical emancipatory approach to voice-hearing, as developed in the work of Marius Romme and the Hearing Voices Movement (see Chapter 3) and will compare and contrast the conclusions of this approach with the existing qualitative literature.

The lived experience of voice-hearing in individuals diagnosed with psychotic disorders

A decade ago, the Division of Clinical Psychology of the British Psychological Society issued a report addressing recent advances in the understanding of psychosis (BPS, 2000). The report noted that psychological services should 'ask about what the [psychotic] experiences mean to the person and how he or she understands them' (p. 60). In recognition of the importance of gaining knowledge of individuals' own understanding of their experiences of psychosis, the decade since this recommendation has seen the emergence of a significant body of research into this area. This has taken the form of qualitative studies where participants are asked open-ended questions about their experiences, and their replies transcribed verbatim and analysed. This starts to allow some voice-hearers' voices to be heard,¹ although it is noteworthy that it is still a

¹ We will examine the debate around hearing voice-hearers' own accounts of their experiences, and the debate over the medical model in Chapter 12.

researcher defining the broad questions, and in many of these studies respondent validation (i.e. asking the participant if they agree with the findings of the study) is not employed. Whilst most studies have studied the general experience of psychosis or schizophrenia, rather than voice-hearing in itself, a picture can still be created from this literature of what the lived experience of voices in people in the psychiatric system is like. Of course, a study of the effects of psychosis on one's life is not necessarily the same as a study of voices on one's life. However, given that the vast majority of people who are given the diagnosis of a psychotic disorder will hear voices, such studies give us a good indication of the struggles and problems that voice-hearers in the psychiatric system are likely to face. Such caveats aside, what does this literature show?

Relationships with voices

Having a voice often means developing a new relationship in one's social world, a relationship of sorts with one's voice. It has been found that patient voice-hearers often develop close relationships with their voices, and react to their verbalisations just as someone would with another person (Benjamin, 1989). Around half of voice-hearers assign names to their voices, again, just as one would with people in the real social world (Chin, Hayward & Drinnan, 2009). Voice-hearers will often be involved in a battle for control and power with their voices. Voices can try and achieve power over the voice-hearer by issuing commands and instructions, and also by having a disturbing 'knowledge' of the voice-hearer's weaknesses, attacking them at this point (ibid.). In response, voice-hearers will employ tactics such as fighting back, or complying with the voices. Many voice-hearers have a sense of closeness with their voices, with one stating that 'I haven't got many friends ... so the only thing I can stay very close to are the voices and I do stay very close to them' (p. 9). However, others reject this sense of closeness, which disturbs them, with one voice-hearer stating that their voices would keep on saying 'that we're all in this together and we're gonna be married with each other for the rest of our lives' (p. 11). Reasons for rejecting this sense of closeness include trying to maintain a sense of self. Going beyond the relationship one has with one's voices, two core themes may be found in the lived experience of voice-hearing, those of loss and regaining.

Loss

Voice-hearing in those who enter the psychiatric system is associated with a loss of many basic human needs, including the loss of safety,

security, hope, social relationships, respect, esteem and a purpose in life. This is not to say that they are necessary losses, but rather that individuals who are distressed by their voices, cannot cope with them, and end up in an illness state, typically suffer such losses.

Loss of consensual reality

Qualitative studies show voice-hearers can report that when their voices start they feel like they have lost the sense of living in the same world as everyone else. When they start, voices' onset may be sharp and noticeable, or more gradual (*ibid.*).² This onset of voices is not necessarily perceived as abnormal, with some people noting voices starting, but regarding them as normal: 'I thought that was just the way I was' (Judge *et al.*, 2008, p. 97). Yet numerous voice-hearers start to feel like they are living in a different reality (Dilks, Tasker & Wren, 2010; Mauritz & van Meijel, 2009), and question this new reality, asking what is real and who the voices are (Jarosinski, 2008). The onset of this new reality is often accompanied by feelings of confusion and fear (Boyd & Gumley, 2007). Fear often remains, or is even amplified, by hospital admission (Laithwaite & Gumley, 2007).

Loss of hope

For those hospitalized as a result of their voices, a loss of hope and motivation is common. The loss of a perceived future is a key reason for the loss of hope. One participant in a study bluntly stated 'I don't have a future' (Knight, Wykes & Hayward, 2003, p. 216). Rice (2008) found that 'a positive future was not something they could easily grasp or shape, and to hope for a "recovery" did not seem possible' (p. 971). Jarosinski (2008) found participants' beliefs that they were 'unable to make it on his or her own', was reinforced by their voices. When voice-hearers receive a diagnosis (often of schizophrenia) this can also destroy hope, being experienced as a 'prognosis of doom' (p. 421), with the way it is communicated to them by mental health professionals often not helping (Pitt *et al.*, 2009). Schulze & Angermeyer (2003) noted that participants in their study, including voice-hearers, criticised diagnoses being given with prognoses such as 'You've got schizophrenia, you will be ill for the rest of your life' (p. 304). The biological model used by professionals can also be associated with determinism and hopelessness

² Hoffman *et al.* (2008b) found 71% of patients could recall the first time they heard a voice, 48% remembered it vividly and 62% were at least moderately upset by this.

(Thornhill, Clare & May, 2004), with some individuals diagnosed with psychotic disorders reporting having had their hopes crushed by clinicians: 'I had a doctor about ten years ago who said I would never work again' (Chernomas, Clarke & Chisholm, 2000, p. 1518), 'one psychiatrist told me I'd only ever do menial work' (Marwaha & Johnson, 2004, p. 309). Indeed, Tooth *et al.* (2003) found nearly two-thirds of individuals in their study (patients diagnosed with schizophrenia) reported health professionals had had a negative impact on their recovery. One reason was the use of 'you can't' messages, which stripped them of any hope of recovery.³ When voice-hearers receive a diagnosis, this can also be associated with a loss or change in identity. Dilks, Tasker & Wren (2010) found a participant who described 'beginning to undergo that radically dehumanizing and devaluing transformation from being a person to being an illness ... to being "a schizophrenic"' (p. 98). Other reasons for loss of hope include loss of employment (Perry, Taylor & Shaw, 2007) and, in the case of mothers with psychosis, having their children taken away from them (Diaz-Caneja & Johnson, 2004). This loss of hope may often lead to a depressed, demotivated state, with McCann & Clark (2004) recording the view of one individual (diagnosed with schizophrenia) who, when asked what they saw themselves doing in the next five years, simply replied 'nothing' (p. 789).

Loss of homeostasis

A number of studies have identified a loss of normal sleeping and eating patterns, and the loss of a normal pain-free state in individuals diagnosed with psychotic disorders (e.g. Koivisto, Janhonen & Vaisanen, 2002), many of whom will be voice-hearers. Medication side-effects are implicated in such changes, with McCann & Clark (2004) quoting one individual remembering that 'I was asleep nearly 18 hours a day' (p. 792). Rofail, Heelis & Gournay (2009) noted that medication could cause patients to be 'hungry all the time' (p. 1491). Physical pain was also a side-effect, with Usher (2001) finding a participant reporting 'What I've been through is like hell ... like a screw being tightened in your brain ... like a pressure point being turned on in your brain ... you feel lethargic and tired but at the same time they give you motor restlessness, it is a weird sensation, you don't feel like getting up to do anything

³ A lack of information or knowledge about how to combat voices may also lead to a loss of hope. Virginia Woolf herself wrote, not long before her suicide, 'I am always hearing voices, and I know I shan't get over it now. I shan't recover this time' (Woolf, as cited in Szasz, 2006, p. 85).

and yet you can't keep still' (p. 148). Roe *et al.* (2009) noted one participant reporting the effect as being 'as if someone pulled the hand brakes in my brain' (p. 41).

Loss of security

Feeling scared and insecure due to the voices themselves is common. Abba, Chadwick & Stevenson (2008) noted that voice-hearers were 'overwhelmed, overtaken, subsumed and defined by a powerful other' (p. 81). One participant stated of their voice, 'it just won't let you lie there and rest ... they're at you 24 hours of the bloody day' (*ibid.*). Voice-hearers may feel especially vulnerable whilst in hospital (Koivisto, Janhonen & Vaisanen, 2004). For example, Thornhill, Clare & May (2004) noted participants diagnosed with a psychotic disorder used 'imagery about imprisonment and torture to describe the experience of treatment within the mental health system' (p. 188), with one patient describing hospital as like a prison where there was continual danger of attack. Financial security may also be lost due to voice-hearers losing their jobs: 'I couldn't hold down a job due to the way I was feeling' (Gee, Pearce & Jackson, 2003, p. 6). Such financial problems also cause problems with one's living arrangements (Laliberte-Rudman *et al.*, 2000), such as having to downsize or move to a worse neighbourhood, making people feel even more insecure.

Loss of relationships

Hearing voices can also cause severe problems with keeping up one's social relationships. This can lead to chronic loneliness at a time when love and belonging is particularly needed (Mauritz & van Meijel, 2009). Gee, Pearce & Jackson (2003) found individuals diagnosed with schizophrenia, including voice-hearers, 'being quiet and not sociable. Not wanting to go anywhere' (p. 8). One reason for this was problems communicating due to the voices. As one participant stated, 'There's sort of voices and all sorts of mayhem going on inside and there's not enough of your brain left to concentrate on what people are saying' (p. 7). As a result, some studies (e.g. Judge *et al.*, 2008) noted withdrawal being used as a coping mechanism. Chernomas, Clarke & Chisholm (2000) found women diagnosed with schizophrenia talking about the loss of relationships with friends and family who 'didn't understand their illness and with the difficulty they now have ... connecting to the world' (p. 306). Similarly, MacDonald *et al.* (2005) found that some individuals diagnosed with psychosis felt

misunderstood by their friends and preferred not to spend time with them. Medication side-effects and diagnosis also impaired relationships, as well as help-seeking. In Usher's (2001) study of individuals diagnosed with schizophrenia, one participant stated that 'I stay at home now and don't go out much because people are sort of put off by the side-effects ... people avoid me or they can't understand me because I slur my words' (p. 149). This also makes voice-hearers feel less able to enter into romantic relationships (Redmond, Larkin & Harrop, 2010). Volman & Landeen (2007) found individuals diagnosed with schizophrenia felt their illness also profoundly impacted on their sexuality, with one problem being medication-related weight gain. They found that social stigma also limited participants' sexual experiences, and that voices could impair relationships. One individual reported that her partner 'tells me that he loves me ... but the voices tell me different' (p. 414). In terms of sex for the purpose of reproduction, Gonzalez-Torres *et al.* (2007) found that this was discouraged in individuals diagnosed with schizophrenia, with one participant saying 'You mention to the psychiatrist that you want to have a child and he says "no, that's not possible, don't even think of it"' (p. 19). Chernomas, Clarke & Chisholm (2000) found that some women diagnosed with psychosis who had chosen not to have children 'because of their illness' were angry, sad, or resigned about this.

Stigma

Stigma is a major problem,⁴ particularly as many voice-hearers receive a diagnosis of schizophrenia. Chernomas, Clarke & Chisholm (*ibid.*) reported that many women chose not to disclose their diagnosis of schizophrenia to others as 'they don't understand ... especially with schizophrenia, they think they're going to be murdered by you' (p. 1518). Judge *et al.* (2008) found participants diagnosed with psychotic disorders would avoid or delay coming to services because people 'would think you was crazy' and 'I pictured myself being locked up in a cell if I told the truth' (p. 98). Rice (2006) found how one participant's diagnosis of schizophrenia was used against them when testifying against an abuser in court, with a participant stating that 'The police just didn't think I was ... a good enough woman to pursue any charges ... Kind of like a lower class citizen ... a degenerate person'. MacDonald *et al.* (2005) also found that individuals diagnosed with schizophrenia felt

⁴ For a good discussion of stigma resulting from the way in which the media portrays hearing voices, see Leudar & Thomas (2000). Also see Chapter 12 on the relation between biological models of voices and stigma.

they were viewed as diminished, with one stating that 'it's like first when Aids came out, "Don't touch those people"' (p. 137). Gonzales-Torres *et al.* reported that individuals diagnosed with schizophrenia felt they were treated like 'oddballs' (p. 18) and similarly Chernomas, Clarke & Chisholm (2000) found that they were labelled as 'an oddball', 'a freak' and 'a weirdo' (p. 1519). In Laliberte-Rudman *et al.*'s (2000) study, one even stated that 'I feel ... like a different species'. Rice (2008) found an individual diagnosed with schizophrenia who felt forced to maintain secrecy surrounding her sexual abuse, stating 'there was nobody I could tell it to, because if you told somebody, even today, they think there's something wrong with you, especially if you're schizophrenic ... you have a disease ... you're trash'.

Loss of autonomy and respect

It was noted in Chapter 3 how the asylum system under Tuke encouraged patients to be viewed as children. This appears still to be the case with individuals diagnosed with psychotic disorders today, who can experience a loss of autonomy leading to their not feeling respected (e.g. Wagner & King, 2005; Warren & Bell, 2000). We find statements such as 'I wasn't told what the medication did ... you were just told to take it' (Powell & Clarke, 2006, p. 362) and 'I feel like a guinea pig' (Rofail, Heelis & Gournay, 2009, p. 1492). Humberstone (2002) reported an individual diagnosed with schizophrenia stating how services 'can treat me like a little child, they can treat me like a spastic, they can treat me like a nothing' (p. 370). Voice-hearers often feel that they are not treated as a whole person: 'they [the nurses] really only come around to give needles as though that's all's needed' (Warren & Bell, 2000, p. 199), 'you are now a schizophrenic and we treat you with medication' (Thornhill, Clare & May, 2004, p. 188). Roe *et al.* (2009) quote one participant arguing 'who are you to decide for me that it is better to be fat and happy to be on the safe side? I want to be skinny with episodes ... give me the right to decide for myself' (p. 41). Voice-hearers' physical complaints may also be dismissed: 'Until they discovered what I have (kidney stones), they didn't listen to me, it was all due to nerves' (Gonzales-Torres *et al.*, 2007, p. 18).

Parenthood

Both mothers and fathers (Evenson *et al.*, 2008) who hear voices and receive a psychotic diagnosis face a number of problems. Diaz-Caneja & Johnson (2004) found mothers were concerned at having to cope with

both with their children and their voices, especially when medication impaired their ability to look after their children, by slowing them down and reducing their concentration. Both Diaz-Caneja & Johnson and Chernomas, Clarke & Chisholm (2000) found mothers worrying that, due to genetic or environmental factors, their children may also become mentally ill, and their great fear of their children being taken away ('they're gone, and you don't think you have a reason to live', p. 1519). Chernomas, Clarke & Chisholm also emphasised the issues for women diagnosed with a psychotic disorder who became pregnant. Those who got pregnant whilst on antipsychotic drugs were faced with a conundrum; one explained, 'I had to continue taking my medication because without my medication I'm helpless ... What harm is my medication going to do to my child? I don't know. But I knew I couldn't stop taking it' (*ibid.*).⁵

Regaining

The qualitative literature also shows the important aspects in recovery from voices, which in part circulate around regaining the ability to re-meet the human needs that voices had led to people not being able to meet. Importantly, whilst for some this may involve getting rid of their voices, for others it may involve coming to be able to cope with their voices and to meet their needs whilst still hearing voices.

Regaining reality and self

Many qualitative studies find medication helps control some people's voices, increase feelings of reality and help clear thinking (Rofail, Heelis & Gournay, 2009; see also Appendix A). However, regaining a sense of reality and control does not necessarily involve getting rid of voices; for some it is a case of dealing with them better.⁶ As noted earlier, Costain (2008) found some voice-hearers used cannabis precisely because it made the voices 'louder and clearer', which helped them to cope with them, as the voices became easier to understand and control. Another important part of coping with voices is making sense of them (see also

⁵ Notably, Pawlby *et al.* (2010) have found evidence that challenges previous conclusions that mothers with a diagnosis of schizophrenia have deficits in their interactions with their babies.

⁶ An important step in recovery may not be the regaining of the same reality as the majority of the population, but rather the recognition by others of the new reality a voice-hearer is living in. Other people recognising that one's voices are a real experience may also be very helpful to the voice-hearer (Coleman, 2000).

Romme *et al.*, 2009). Sharing the voice-hearing experience with others who do not doubt or question them is important (Dilks, Tasker & Wren, 2010) and voice-hearers commonly seek the company of peers with shared experience (MacDonald *et al.*, 2005). Sense-making is sometimes helped by diagnosis, which can be seen as legitimating participants' experiences (Pitt *et al.*, 2009). Achieving distance from voices, accepting them without being too 'impressed' by them (Roe, Chopra & Rudnick, 2004, p. 125) and mindfulness/detachment have been found to help: 'I just decided to observe basically within myself, just to be aware, and to allow the voices to say whatever they wanted to say' (Nixon, Hagen & Peters, 2010b). Thornhill, Clare & May (2004) described how regaining the self involved escaping the role of a psychiatric patient, which could happen suddenly, with one participant explaining their decision to just 'let go ... of being that mad' (p. 189).

Regaining hope

The importance of regaining hope is clear, evidenced by voice-hearers' statements, such as 'when ... you're hearing voices ... sometimes hope is the only thing you've got' (El-Mallakh, 2006, p. 61). Hope can come back suddenly; 'there was a flash in my mind. I was so sick of being mistreated by everyone that I thought to myself, "Enough is enough"' (Noiseux & Ricard, 2008, p. 1153) or gradually (Gould, DeSouza & Rebeiro-Gruhl, 2005). The support of friends and family can be crucial to hope returning (Wagner & King, 2004). Medication can also give hope (Usher, 2001), as can religion or spirituality (Humberstone, 2002). As one individual put it, 'If I had no faith, I don't know how I'd get through it. No faith, no hope, no light at the end of the tunnel. I would end it' (Drinnan & Lavender, 2006, p. 323). Powell & Clarke (2006) found that having an understanding that other people are going through the same thing instilled hope. One participant in their study stated that 'reading experiences where people had recovered, it was such a boost, because you thought well, if they can do it, you know, I will be damned if I can't' (p. 363). Schon, Denhov & Topor (2009) revealed that meeting others in the same situation as themselves could give participants 'living proof' of hope. Here we see the importance and inspirational value of recovered voice-hearers (who do or do not still hear voices) who act as positive role models.

Regaining employment

A common theme in studies of individuals diagnosed with psychotic disorders, and hence voice-hearers, is the desire to get back to work

(Marwaha & Johnson, 2005). As one participant in the study of Dilks, Tasker & Wren (2010) put it, 'I want to get back into work, I want to get back into a normal, stable life' (p. 95). Work is often associated with a feeling of being normal, and can be seen as a way of coping (Roe, Chopra & Rudnick, 2004). Several studies have identified barriers to returning to work, with stigma playing a key role. Often voice-hearers will not mention their illness to employers, because 'You wouldn't get taken on in the first place if you told them you had a big mental history' (Marwaha & Johnson, 2005, p. 309). Chernomas, Clarke & Chisholm (2000) identified the barrier of the perceived risk of losing welfare benefits, with one participant diagnosed with schizophrenia stating, 'I want to try to find a job, but I'm scared ... that I'm going to get sick and I'm going to lose my job, and I'm going to have no money and how am I going to get back on welfare?' What voices say can also be a barrier in getting back to work: 'My first priority is to get rid of the voices and then work' (Gioia, 2006, p. 170). Rofail, Heelis & Gournay (2009) also found that medication side-effects impaired some participants' ability to work: 'They make me feel too tired to work my skilled job' (p. 1491).

Regaining relationships, and recovering through them

Friends, family, and the need for constancy, for someone who voice-hearers know would 'be there' (Lencucha *et al.*, 2008, p. 345) are all important. Many voice-hearers may create new and enduring friendships with people who share similar voice-hearing experiences (Nixon, Hagen & Peters, 2010a). Indeed, Lencucha, Kinsella & Sumsion (2008) found that participants diagnosed with schizophrenia identified their most important relationships as being ones with people who had knowledge of living with psychosis. Knight, Wykes & Hayward (2003) also found that solidarity with others was important. One participant diagnosed with schizophrenia referred to their peer-support group for people who heard voices as giving 'solidarity in people' (p. 217). Although Tooth *et al.* (2003) found that nearly two-thirds of participants reported that health professionals had a negative impact on their recovery: 'it was the psychiatrist versus us lot [the patients]' (Knight, Wykes & Hayward, 2003, p. 214), Nixon, Hagen & Peters (2010a) found that the majority of participants diagnosed with psychosis in their study stated that mental health professionals were instrumental in their recovery, highlighting the friendship aspect to their relationship with helpful professionals. One participant described how her psychologist did not act as a condescending expert, but 'talked like a friend to me'. Similarly, O'Toole *et al.* (2004) found that being 'treated like a human being' (p. 321) by mental health

professionals was a key to recovery. Being listened to was also important for recovery (McGowan, Lavender & Garety, 2005).⁷

Beyond regaining: the gifts of voices

A number of studies found that voice-hearers with diagnoses of psychotic disorders talked of the gifts that came from their experiences (Woodside, Schell & Allison-Hedges, 2006). Nixon, Hagen & Peters (2010a) found some participants could now connect with their sense of creativity (e.g. through writing about their experiences) and that this was associated with their path to recovery. Some participants also noted the help of spirituality to their recovery, and as a result viewed their psychosis retrospectively as a spiritual gift. Nixon, Hagen & Peters (2010b) also described how some participants 're-aligned their career path to reflect their newfound spiritual awareness'. One participant stated that, 'I don't think I was creative until that [my psychosis] happened'. Voice-hearers may also try to help others with mental health concerns, or become advocates for other service-users, reflecting their increased compassion (Nixon, Hagen & Peters, 2010a). We will examine these aspects more in Chapter 12.

Conclusion

In conclusion, we can see that for voice-hearers who are unable to cope with their voices and who enter the psychiatric system, this can have a pervasive effect on their lives, leading to an illness state. In fact, the experience can be seen to impact upon all of Maslow's (1943) basic human needs. First, basic physiological needs can be affected (such as sleep impairment, physical pain, etc.). Second, one's security needs are not met. This can include losing one's job and hence one's financial security, having to move into worse housing and neighbourhoods, and physical changes to the body and one's health often due to medication side-effects. Third, the need for love and belonging is frustrated due to the impact of the voices on one's ability to function, and the stigma which is associated with the experience. Fourth, one's need for esteem is blocked by stigma affecting how other people view you, what you might come to think of yourself, and what the voices tell you. The need for self-actualisation, i.e. to create, live and be all you can be, is also often blocked. Recovery is hence a long journey to get all this back, and not

⁷ See Chapter 12 for problems voice-hearers have being listened to.

an easy one. As Milton (1821) put it, 'Long is the way/And hard, that out of hell leads up to light' (p. 47). Once these needs are met again, the voices may have given the person gifts, which they can use to enhance their life and, in Maslow's terminology, get closer to self-actualisation than they were before.

How, then, is recovery to be achieved? Aside from the regaining of basic human needs, this depends in part on what recovery means for the individual voice-hearer in terms of their relationship with their voices. This may range from the desired elimination of the voices,⁸ to simply being able to cope with (and not eliminate) the voices, to the successful addressing of emotional issues that potentially underlie the voices.⁹ One tool, as highlighted in some of the qualitative accounts above, is anti-psychotic medication. Rigorous quantitative studies of the effectiveness of antipsychotic medication will be examined in Appendix A, and the subjective impact of such medication on voices and the possible biological mechanisms underpinning this action will be discussed in Chapter 8, when we move on to look at the biological causes of AVHs. There is also some evidence that cognitive behavioural therapy (CBT) is also able to reduce the frequency of voices in some cases, and can help people cope better with their voices although, as we will see in Chapter 12, quantitative randomised controlled trials of CBT for AVHs show disappointing results. Before we come on to these quantitative studies later in the book, it is worth noting here that in cognitive models of voice-hearing it is the appraisal of voices rather than the voices per se that is seen as the cause of problems and distress (e.g. Byrne *et al.*, 2006). This conclusion is reinforced by the findings in the next chapter, that many people can function well whilst hearing voices. Thus, voices in themselves may not be pathological, but the inability to cope with them or dysfunctional coping may result in a state that can be labelled illness. In this way recovery may not be a matter of changing oneself from a voice-hearer into a non-voice-hearer, but changing from being a patient voice-hearer into a healthy voice-hearer. That this could validly be considered recovery is what Romme and colleagues have referred to as the emancipation of voice-hearers (Chapter 3; Romme *et al.*, 2009). Given that Romme and colleagues' work on recovery is based on their personal and clinical experience, as well as individual case-studies

⁸ Although some voice-hearers report feeling lonely when this desired outcome has actually happened (e.g. see Byrne *et al.*, 2006, p. 83).

⁹ Furthermore, as well as the voice-hearer's recovery, it has been argued that society also needs to recover from its stigmatisation of voice-hearing to allow the voice-hearer the freedom to walk the street talking to their voices (see Coleman in James, 2001).

(and their work can be seen as more qualitative than quantitative, hence showing a resemblance to the studies reviewed above), their conclusions will be examined here. An important question is how their conclusions as to how recovery can be achieved differ from that found in the review of qualitative accounts discussed above.

Changing the lived experience of voices: Romme's emancipatory approach

Writers within the Hearing Voices Movement, as described in Chapter 3, have argued that 'getting rid of voices is neither necessary, nor that important' (Romme *et al.*, 2009, p. 7). Such writers argue instead that one must change one's relationships with one's voices. This forms part of the Maastricht approach, which we will discuss further in Chapter 12. An important publication relating to recovery within the ethos of the Hearing Voices Movement is *Living with voices: 50 stories of recovery* (Romme *et al.*, 2009), which should be required reading for anyone involved in this area. Based on their review of 50 voice-hearers' own stories of recovery, Romme and colleagues identify nine issues which they argue are important in helping an individual to recover from the distress associated with voices. Many of these are consistent with the conclusions from the review of qualitative studies above. First, Romme *et al.* conclude that *Meeting someone who takes an interest in the voice-hearer* is important. This is consistent with the findings of the first half of this chapter, which showed that being treated as a whole person, rather than simply a drug pin-cushion, was reported as being important to recovery. Second, Romme *et al.* note that *Giving hope, by showing a way out and normalising the experience* is needed. Again, this accords with the crucial importance of hope noted in the first half of this chapter. *Meeting people who accept the voices as real; being accepted as a voice-hearer by others, but also by oneself* is Romme *et al.*'s third criterion. This is consistent with the need to overcome stigma, and the benefits of talking and meeting with others who have the same experience, noted in the first half of this chapter. Romme *et al.* also highlight that *Making choices* is important to recovery. By this they mean that choosing to stay alive, choosing which friends one wants, choosing to develop one's self, choosing to get a job, etc., are important. This adds to the qualitative findings reviewed above by highlighting that the ability to recover human needs has an important step between hoping for recovery of these needs and achieving these needs, namely the need actively to choose to undertake this journey (see also Coleman & Smith, 1997).

Importantly, the qualitative literature reviewed in the first half of this chapter fails to note five (i.e. over half) of the issues that Romme *et al.* (2009) propose are important in recovery, all of which involve the voice-hearer actively engaging with their voices and emotions. These are *Becoming actively interested in the hearing voices experience*, *Recognising the voices as personal and becoming the owner of your voices*, *Changing the power structure between you and your voices*, *Changing the relationship with your voices*, *Recognising your own emotions and accepting them*. The reason for the qualitative literature not identifying this appears to stem from the different philosophies employed by the majority of the authors of qualitative research and Romme *et al.* Central to their approach (Chapter 3, Chapter 12) is that voices are meaningful experiences, related to the emotions and events in the voice-hearer's life. They argue that recovery can only be achieved by working with the voices, understanding them and their relation to one's own emotions and past, and changing one's relationship with them. This can be achieved both by talking directly to the voices (e.g. using the technique of voice dialogue – see Chapter 12), as well as using clues given by the voices (i.e. their content, age, etc.) as to their relation to events in the voice-hearer's past, which then need to be resolved. Such an approach is generally in contrast to the majority of the qualitative literature, which tends to focus on the negative consequences of the voices, implicitly or explicitly assuming that the way to recover these is hence to eliminate the voices. Here we see radically different routes to recovery. Although the early informal results of Romme's approach appear positive, moving forward there is the need to clearly test its effectiveness in a large-scale randomised controlled trial.

Chapter 5: summary of key points

- Voice-hearing in individuals who are distressed and unable to cope with them (and have hence become psychiatric patients) leads to the loss of basic human needs.
- These include a loss of control over one's mind and body, a loss of security and safety, a loss of social and romantic relationships, a loss of hope and a loss of respect.
- These basic human needs are lost not only due to the direct effects of the voices, but due to factors such as stigma, misunderstanding and negative experiences in the mental health system.
- The process of recovery is likely to be the process of regaining the ability to achieve these needs.
- Hope and positive social relationships are key to the recovery process.

- The voice-hearer who has recovered may or may not still hear voices, and can achieve growth and personal development from the experience they have been through.
- Existing peer-reviewed qualitative studies differ from Romme and colleagues' emancipatory approach to voice-hearing by failing to consider the need to engage with and change one's relationships with voices.
- It may be that the important transition is not from voice-hearer to non-voice-hearer, but from patient voice-hearer to healthy voice-hearer.
- Large-scale randomised controlled trials of Romme *et al.*'s recovery model of voice-hearing are required.

6 Beyond disorder: religious and cross-cultural perspectives

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (APA, 2000) is clear to stress that clinicians must take account of cultural factors when making a diagnosis. The authors of the DSM note that, 'In some cultures ... auditory hallucinations with a religious content may be a normal part of religious experience' (p. 306) and give the example of hearing God's voice. Thus, although Szasz (1996) famously quipped that 'If you talk to God you are praying; if God talks to you, you have schizophrenia' (p. 13), the DSM allows that one may hear God's voice and that if this is culturally acceptable, then this is not a sign of mental disorder. But how many people hear what they believe to be God's voice? How do religions today treat the experience of hearing voices (Christianity and Islam will be focused on here), how prevalent is voice hearing in other cultures and how is the experience understood and coped with in these cultures? These are the questions this chapter will set out to examine.

Contemporary religion and hearing voices: Christianity

Evangelical Christianity and hearing the voice of God

The allowance by the DSM that hearing the voice of God may be a normal part of experience in a culture opens the door to a serious study of what leads contemporary individuals to report hearing the 'voice of God', and what this experience is like. In a study of 29 members of an evangelical Christian church, who reported having no previous treatment for mental illness, Davies, Griffin & Vice (2001) found that 59 per cent reported hearing voices. This compared to a rate of 27 per cent in a non-religious control group. The experience of hearing voices was significantly more positive in evangelical Christians than in both non-religious controls and patients diagnosed with psychosis. Interestingly, both the evangelical Christian group and the patients diagnosed with