Coping with voices: an exploratory pilot study

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Abstract

Hearing voices is an experience common to many people in psychiatric care but meaningful help in coping with the experience is less common. This paper presents a model of coping behaviour specific to hearing voices. It proposes that coping with voices includes hallucinatory control, emotion and problem focused coping and is a function of context, the features of voices, and beliefs about voices. Results from a pilot study exploring coping with voices are presented. A questionnaire which combined previously tested scales including voice topography (Hustig & Häfner, 1990), beliefs about voices (Chadwick & Birchwood, 1995) and general coping behaviour (Carver, Weintraub, & Sheier, 1989) was administered to 10 consumers of a mental health service with a recent history of hearing voices. The instruments were found to be reliable and easy to complete. Results are discussed in relation to the theoretical framework and suggest that people engage in a wide range of purposeful coping behaviour in response to voices that do not fit comfortably into arbitrary coping categories. Consideration of 'coping with' rather than 'amelioration' of voices ought to be a key focus of nursing, and the model of coping presented may be useful in making sense of, and facilitating coping behaviour.

Hearing voices is an unusual experience that can be emotionally stressful, and which few people are equipped to cope with through prior learning. Nurses and other health professionals who would wish to support people in coping with voices are constrained by a paucity of research to inform their practice. This pilot study (completed in 1999) began to explore how people who hear voices cope with the phenomenon.

Hearing voices is a common experience of people in psychiatric care and is a particular feature of the psychotic disorders, which are the most prevalent class of medical diagnosis for those receiving in-patient care in New Zealand (Disley, 1997). In Australia, between 4 and 7 people for every 1000 adults resident in urban areas are in contact with mental health services during any given month because of symptoms of a psychotic disorder (Jablensky et al., 1999). In a sample of 980 people with psychotic illness in Australia, 96% had experienced symptoms such as delusions and hallucinations at some point, 61% were experiencing these currently, and for 43% there was no complete recovery between psychotic episodes (Jablensky et al., 1999). Whilst clearly, a phenomena of concern to psychiatry, hearing voices may also be reported by people who do not regard themselves as mentally ill and have no other psychiatric symptoms (Romme & Esher, 1989). Some estimates suggest up to 70 % of the population may experience auditory hallucinations at some time and voices, are estimated to be experienced regularly by around 4% of the population (Nelson, 1997, p.179).

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Despite recent advances in the pharmacological treatment of psychotic illness complete and sustained amelioration of voices in chronic mental illness is seldom possible (Westacott, 1995). Furthermore, it has been estimated that between 24-80% of "severely and persistently mentally ill" people in the community do not take psychotropic medication as prescribed (Mulaik, 1992), with side effects often stated as the reason for non-compliance (Sederer & Centorrino, 1997). Health professionals are often challenged to assist people cope with and make sense of hearing voices despite pharmacological treatments. For some people assistance with coping will be adjunctive to pharmacotherapy, whilst for others coping enhancement ought to be the primary intervention.

Although hearing voices may appear to be a dramatic and easily assessable manifestation of mental illness, Tollefson (1996) points out that cognitive impairment rather than florid psychotic or positive symptoms appear to be most strongly related to poor psychosocial outcomes in schizophrenia. Hearing voices appears to be an experience that many people can adapt to and learn to cope with. Romme et al. (1992) found that a third of people, who claimed to hear voices and responded to a Dutch television request to talk about their experience, coped without recourse to psychiatry.

A growing consumer movement considers that an attitude of acceptance is central to living with voices (Baker, 1995; Romme, 1998; Romme & Esher, 1989; Romme et al., 1992). The voice hearing experience is conceptualised by the 'Hearing Voices Network' as "…part of a pattern of personal growth and as a facet of human experience..." (Parker, Harper, Georgaca, McLaughlin, & Stowell-Smith, 1995, p.123). This is exemplified by Pembroke (1998, p.30), who states "My voices belong to me and can no more be removed or treated than a person's sexual orientation…. It is not the hearing of voices that is the problem, it is the inability to cope with them". Whilst these claims may sit uneasily beside medical discourse which formulates voice hearing as a "residual or drug resistant symptom" (Parker et al., 1995, p.125), to be useful to the person, the nurse must consider what it means to cope with voices. This is congruent with the purpose of nursing which Travelbee (1979, p.7) described, " …an interpersonal process whereby the professional nurse practitioner assists an individual, family, or community to prevent or cope with the experience of illness and suffering and, if necessary, to find meaning in these experiences." Clearly coping with voices involves more than controlling the experience.

Theoretical Framework

The framework of stress and coping proposed by Lazarus and Folkman (1984) and further developed by Carver, Weintraub, and Sheier (1989), as well as Slade's (1976) explanatory model of hallucinations provided the theoretical framework for this study. For the purposes of this study coping was as a purposeful activity, in response to the appraisal of some aspect of the voice hearing experience as stressful.

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Context

Voice hearing occurs in social and cultural context. Whilst hearing voices has come to be associated with psychiatric illness in the west, illness is not a universally accepted explanation. Throughout history voice hearers have influenced the development of humanity, including people such as Socrates, Plato, Joan of Arc, Carl Jung, Winston Churchill and Adolf Hitler (Baker, 1995). Even Florence Nightingale, is reported to have been influenced by hearing voices (Woodham-Smith, 1952, p.14). The way the experience is constructed and explained, as well as the person's position in society will influence whether or not the person who hears voices is accepted or considered deviant in some way.

Cultural beliefs invariably influence coping and help seeking behaviour. A comparison of coping strategy use between Saudi Arabian and UK patients whom heard voices (Wahass & Kent, 1997) found that Saudi Arabian patients used strategies associated with their religion whereas UK patients were more likely to use distraction or physiologically based approaches. It has been suggested that cultural attitudes towards hallucinations affect the person's emotional reaction, the degree of control over the experience, and that therapists should consider the functional significance and meaning of hallucinations as well as the social context and the stimuli associated with them (al-Issa, 1995). Stress and coping, occurs against a cultural and social background, which must be acknowledged. Indeed groups such as the HVN exhort cultural change so that hearing voices is accepted in society.

Emotion and problem focused coping

According to Lazarus and Folkman (1984) coping strategies may be categorised as emotion focused (orientated towards regulating distressful emotions), or problem focused (behaviour aimed at solving the problem that is causing the discomfort). Carver, et al. (1989) have argued that some types of coping behaviour such as venting of emotion or behavioural disengagement do not fit comfortably into either category and may have either positive or negative effects on emotional state and the stressor. Carver, et al. (1989) identified 13 factors, which they claim, are conceptually distinct ways of coping but which may be classified as problem, emotion focused or other ways of coping. Each of these factors may be assessed using the COPE questionnaire (See Table 1), which was a key instrument in this study.

Strategies employed from one situation to another may reflect relatively stable dispositional tendencies, although strategy use is likely to vary from situation to situation (Carver et al., 1989, p.277). Emotion focused coping may be more effective in circumstances where a stressor is uncontrollable and problem orientated coping more effective in situations where a problem is amenable to solution. There is now a considerable body of evidence that voice hearers can exert at least some control over voices.

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Table 1: COPE Factors (Carver, et al.,1989)

Problem focused coping:	Emotion focused coping:	Other factors:
• Active coping	• Seeking social support for emotional reasons	• Focus on and venting of emotions
• Planning	• Positive reinforcement and growth	• Behavioural disengagement
• Suppression of competing activities	• Acceptance	• Mental disengagement
• Restraint coping	• Denial	• Alcohol-drug disengagement *
• Seeking social support for instrumental reasons	• Turning to religion	• Humor *

* Alcohol-drug disengagement and humor have been added to COPE since publication

Control over hallucinations

Slade (1976) proposed a four factor explanatory model of hallucinations, which may be a useful working model in understanding the factors involved in the development and control of hallucinations. This model proposes that hallucinations arise under conditions of heightened arousal (factor 1) in individuals with a predisposition or vulnerability (factor 2) to hallucinate. The prevailing level of external stimulation (factor 3) determines whether a hallucination is experienced in consciousness. A subsequent reduction in arousal has a reinforcing effect (factor 4) which lowers the threshold for future hallucinations. Slade's (1976) theory suggests that reducing internal arousal may reduce the potential for voices to occur. Thus, strategies directed at regulating emotion (emotion focused coping) may play a role in solving 'the problem' of voices especially when voice hearing is appraised as stressful.

Cognitive appraisal and coping with voices

Chadwick and Birchwood (1997; 1995a; 1995b) have developed the idea that beliefs about voices are central in determining people's coping efforts. They have described two dimensions of coping – engagement with voices, or resistance to voices. They have found that voices perceived as benevolent are likely to lead to engagement behaviour (for example courting them and evoking amusement), whereas those that are perceived as malevolent are resisted (for example evoking avoidance, anger and despair). They suggest that in many cases beliefs about voices are at odds with voice content, and that meanings are constructed by individuals rather than being directly voice driven.

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Drawing the elements together

Consideration of the various dimensions of coping, beliefs about voices, appraisal and attribution of meaning to the experience and an understanding of the aetiology of hallucinations, are all necessary to understand coping. Figure one illustrates how these elements may be related. The features of voices are likely to have a relationship with beliefs about voices. Beliefs about voices will influence the types of strategy chosen to cope. Beliefs are also likely to be shaped by the context in which the experience occurs, cultural understandings and prior experiences. At least some problem and emotion focused coping strategies may lead to varying degrees of control over the hallucinatory experience. The efficacy of these strategies may be best explained using a model of hallucinatory aetiology, for example coping strategies to reduce distress or arousal may reduce the intensity of hallucinations. These related factors were incorporated into the design of this study and guided the analysis of data.
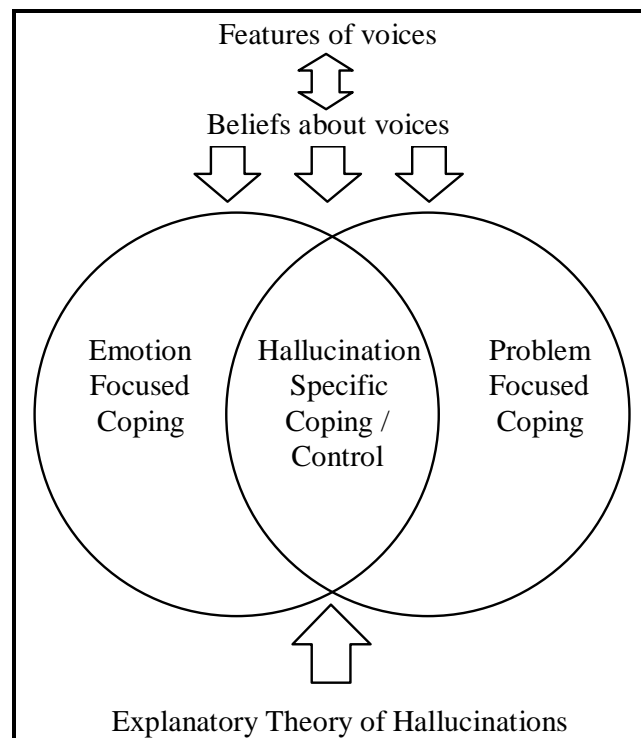
Figure 1: A conceptual map of coping with voices

Overview of method

Potential participants with a recent history of hearing voices were referred by psychiatrists within Hawkes Bay Mental Health Services for consideration of whether or not they wished to be involved in the research project. Ethical approval

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was obtained from the Massey University Human Ethics Committee and the Hawkes Bay Health Funding Agency Ethics Committee as well as approval from managers within Health Care Hawkes Bay and cultural advisors. The protocol for recruitment closely followed that recommended by (Warren & Allan, 1997).

The research instrument consisted of a questionnaire comprising 103 items, which included three distinct and previously validated scales:

- Features of voices – The Topography of Voices Questionnaire (Hustig & Häfner, 1990)

- Beliefs about voices – The Beliefs about Voices Questionnaire (BAVQ) (Chadwick & Birchwood, 1995)

- Coping in response to voices – COPE (Carver et al., 1989)

The COPE and BAVQ included the factors as sub-scales described earlier. In addition questions were asked to obtain basic demographic information (using New Zealand census questions) and an additional question requesting a global self-appraisal of coping with voices.

Overview of sample and results

Three females and seven males completed the questionnaire. The age of respondents ranged from 25 to 61 years (Mean = 41.6) and the age when respondents first reported hearing voices ranged from 4 years to 56 years. The number of years respondents claimed to have heard voices ranged from 1 to 46 years (Mean = 16).

Two respondents identified themselves as New Zealand Maori, seven as New Zealand European / Pakeha and one as 'other' European. The two youngest respondents (aged 25 and 27) stated that their medical diagnosis was drug induced psychosis, six identified their diagnosis as "schizophrenia" (no subtypes identified), one was uncertain and the oldest respondent identified her diagnosis as bi-polar affective disorder.

It is beyond the scope of this paper to present a detailed account of the results. The following are some of the key findings:

In this study each item of the BAVQ was scored on a four point scale (0-3) rather than the dichotomous scale (0-1) used in its original form. The internal consistency of the BAVQ sub-scales calculated using these research data was remarkably consistent with the Alpha scores reported by Chadwick and Birchwood (1995, p.774; original alphas in brackets): 0.82 (0.82) for Benevolence, 0.81 (0.86) for Malevolence, 0.86 (0.84) for resistance and 0.73 (0.87) for engagement. Alpha reliability scores for COPE were consistent with those obtained by the authors of the scale but were reasonably weak.

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Six people rated their coping with voices as fairly poor (n=4) or not at all (n=2). Four respondents had experienced voices for four or less years (M=2.3) and six had experienced voices for considerably longer (M=25.2). There were differences between these two groups with those with less experience tending to rate their coping as poorer (U=2, p<0.05), the voices as more intrusive (U=2.5 ,p<0.05), louder (U=3 , p<0.05), and more malevolent (U=3, p<0.05). Those that had experienced voices for longer were more likely to use religion to cope (M=7.5 vs 2.5, U=0, p<0.5), and less likely to use alcohol (M=3.8 vs 8, U=2, p<0.5) and behavioural disengagement (M=3.7 vs 8.3, U=1, p<0.5) coping strategies.

Voices perceived as benevolent were significantly related to engagement feelings (r_s=.922, p<.01), whereas voices perceived as malevolent were associated with resistance feelings (r_s=.890, p<.01) and behaviour (r_s=.748, p<.05). Self-rated coping was positively associated with benevolence (r_s=.725, p<.05), and engagement feelings (r_s=.750, p<.05). In contrast, self-rated coping was negatively correlated with malevolence and resistance sub-scales of the BAVQ. In terms of features of voices, intrusiveness appeared to yield the strongest linear relationships with BAVQ sub-scales and was positively associated with malevolence (r_s=.800, p<.05), resistance feelings (r_s=.888, p<.01) and resistance total (r_s=.810, p<.01).

Wide ranges of scores were obtained on all COPE sub-scales. Benevolent voices were negatively correlated with most COPE sub-scales and malevolent voices were positively correlated with most sub-scales (except religious coping, rs=-.661, p<.05). Malevolent voices were associated with venting of emotion (rs=-.801, p<.01), behavioural (rs=-.666, p<.05) and mental disengagement (rs=-.830, p<.01) and alcohol and drug use (rs=-.834, p<.01). Religious coping was negatively associated with resistance total (rs=-.817, p<.01) , whereas a positive relationship was found between alcohol / drug use and resistance. Seeking emotional support was negatively correlated with the voice's power (rs=-.707, p<.05).

Discussion

This exploratory research project had a number of limitations, which have a bearing on the interpretation of results. The sample was purposive, convenient, and random procedures were not utilised. Therefore, it cannot be assumed that this group of respondents are representative of voice hearers in general or even those people involved with local mental health services.

Congruent with Warren and Allen's (1997) recommendations, this protocol emphasised employing clinicians to undertake selection of potential clients. In order to secure approval from the service for the research to take place, consultant psychiatrists, rather than 'key workers' or nurses were used to screen potential participants. A considerable amount of energy was expended cajoling psychiatrists to refer clients and in this instance, reliance on third parties for screening with no personal investment in the research was an obstacle to recruiting participants.

Participants appeared keen to talk about their experience of hearing voices. Two respondents commented that this was the first time that anyone had enquired

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about how they coped with voices. The questionnaire provided a safe means for exploring general coping and to explore the validity of the theoretical framework on which this research project was based.

A key problem with much research on coping is that it is seldom clear what it is about hearing voices that people are challenged to cope with. The frequency, volume, clarity and distress associated with voices were all positively associated with intrusiveness. Hustig and Häfner (1990, p.265), also used a small sample of 12 people with persistent hallucinations and found that "…the more intrusive the hallucinations of voices, the more distressing they were, and the more anxious and depressed were the patients". Intrusiveness of voices appears to be a potentially useful clinical concept and it may be hypothesised that the more intrusive the voices the greater the impact the voices will have on day to day functioning.

Birchwood and Chadwick (1997) interviewed 62 voice hearers with diagnosis of schizophrenia or schizoaffective disorder and had them complete the Beliefs about Voices Questionnaire, Hustig and Häfner's scales and the Beck's Depression Inventory. Their research differed from this present research in that items of the BAVQ were scored as 'yes or no' for the dominant voice, whereas in this project respondents were asked to consider all their voices and rate each item on a four point scale. Consistent with Birchwood and Chadwick's (1997) findings, no significant associations were found between benevolent, or malevolent voices and the frequency, loudness or clarity of voice activity. However, Birchwood and Chadwick (1997) did not report on the findings related to intrusiveness. In this research a significant positive relationship was found between malevolence scores and intrusiveness, and resistance coping behaviour and intrusiveness. Birchwood and Chadwick (1997, p.1348) concluded that beliefs about voices, and not voice activity per se, hold the key to understanding the affect and behaviour they generate. Whilst the findings of this research do not refute the dominance of beliefs about voices in determining coping behaviour they do suggest that the relationship between intrusiveness of voices and beliefs about voices requires further exploration.

The longer that respondents had experienced hearing voices the more positively they rated their coping efforts. Over time people may be expected to habituate or adapt to regular stressful events although longitudinal studies are necessary to confirm this assumption. Peplau (1989), described phases of development of voices founded on an assumption that voices are invented in periods of extreme stress, in the absence of a real helping person. The voices give some immediate relief from distress, are courted and the person may become increasingly withdrawn and autistic, losing the ability to discern between real and imaginary voices, leading finally to a failure to conceal the voices from others. Peplau (1989) also asserted that over time voices were likely to become derogatory, accusatory and persecutory which is consistent with Nayani and David's (1996) conclusions that voices develop over time, becoming increasingly personalised, detailed in dialogue with or about the person, increasingly encroach into the person's life, and that these changes are associated with a lessening of distress. Whilst those who had heard voices for more than four years did report less distress than those with more recent experience, they also experienced them as less loud, frequent, clear,

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intrusive and malevolent. Those that had heard voices longer were more accepting of them, perceiving them as more benevolent and reported more engagement than resistance behaviour in response to them.

The presence of benevolent voices was positively associated with self-rated coping as was engagement. It is not surprising that the more positive a person perceived the intent of their voices, the more they were likely to engage with them and the more positively they rated their coping. Benevolence was also negatively associated with distress and intrusiveness. As mentioned earlier malevolence was positively associated with distress, intrusiveness, resistance, and was negatively associated with self-rated coping. Those that experience voices as having malevolent intent are challenged to cope with the negative emotions that may arise. Intrusiveness may pose a somewhat different challenge in relation to focusing on activities of daily living.

There was considerable diversity in people's responses to the COPE questionnaire, which asked respondents whether or not they engaged in particular behaviours when they heard voices. There is no way of ascertaining from the data whether these responses were typical of their responses to other stressful events. What can be concluded is that these respondents engaged in a wide range of purposeful behaviour in response to hearing voices. Farhall and Gehrke (1997) interviewed 81 people who heard voices and categorised coping responses into 12 general categories based on the factor analysis of coping by Carver, Weintraub and Scheier (1989), and concluded that unprompted coping strategies were distributed across all categories of coping except 'positive re-appraisal'. The use of the structured COPE questionnaire effectively prompted participants to consider their coping behaviour and responses were distributed across all sub-scales. Consistent with Farhall and Gehrke's (1997) conclusions these findings do not support a simple problem or emotion focused grouping or a simple general and hallucination specific division of coping. Nevertheless, sub-scales of COPE did correlate in conceptually meaningful ways. For example, those that scored high on religious coping scored highly on sub-scales of acceptance; Those that scored highly on alcohol and drug coping tended to score highly on mental disengagement coping.

Acceptance had the highest mean score of the COPE sub-scales followed by positive reinterpretation and growth and active coping. Acceptance was also the strongest factor in Farhall and Gehrke's (1997) research, only just failing to significantly predict hallucination control. Seeking social support for emotional reasons had the lowest mean score. This ought to be disturbing to health professionals who often perceive themselves as providers of emotional support. Participants in this project reported that they seldom sought emotional support, which perhaps relates to the stigma associated with voice hearing. Interestingly distress relating to voices was positively associated with problem focused coping. It may be that distress prompts people to make attempts at solving problems, or that frustrated attempts at controlling voices leads to greater distress.

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Recommendations and conclusions

Clearly a much greater sample size would have improved this research, and yielded more meaningful and statistically reliable results. A future replication ought to include some form of randomised sampling and be of larger sample size. However, this research project did yield some interesting results, which are worthy of further exploration. The concept of 'intrusiveness' of voices is one, which may prove to be important in terms of understanding coping behaviour. How voices intrude, effect people's lives and what works to lessen this intrusion requires further exploration. The role that acceptance plays in coping with and adapting to voices, and how health professionals may facilitate a positive acceptance of voices also needs to be determined.

This research does lend support to the idea that people cope with voice hearing in idiosyncratic ways, which are not greatly different to how they might respond to any stressful event. Health professionals need to be alert to behaviours, such as alcohol and drug use, or religiosity having a potential role to play in coping, rather than being merely symptomatic of disease. The respondents in this research stated that they engaged in such behaviours in response to voices, presumably with an expectation that they might be of help. The actual outcomes of behaviour in relation to voices, or distress could not be determined with the methodology used. Further research ought to explore outcomes of behaviour in response to voices.

Completing the questionnaire did not appear to pose any problems to respondents. In clinical practice these scales could be adapted for self-monitoring, increasing self-awareness and as a method to promote discussion and insight into people's coping behaviour. People's coping endeavours include more than attempts to control voices. Health professionals need to collaborate with voice hearers in exploring how voices impact on their lives and exploring their full repertoire of coping responses, including those which assist in regulating emotion, control voices and those which may ultimately have adverse effects.

Acceptance of hearing voices may be an important part of adapting to and coping with the experience. Health professionals ought to consider whether current practice assists in promoting acceptance. Respondents in this research scored lowest on the scale related to seeking social support for emotional reasons. Whilst, the reasons for this require further exploration, it may be that the relatively high level acceptance of voices by these people, may be perceived to be at odds with that of others including health professionals. A collaborative relationship aimed at enhancing coping will be difficult to establish if health professionals are perceived as not accepting voices. A climate in which voice hearers are free to discuss their experiences without fear of being labelled as 'ill' or 'deteriorating' is necessary. Health professionals should not presume that the voices themselves are negative and need to be ameliorated. This may ultimately be an outcome, but such judgements should be deferred in the interests of exploring what aspects of the experience are causing distress or challenging coping.

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