From Voice Hearers to Voice Listeners: The Evidence base for the benefits of working with voice-hearers in developing coping strategies and acceptance: A literature review, October 2012

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1. Introduction

This is a literature review intended to provide an overview of evidence base for the assertions made on behalf of the hearing voices approach.

2. The hearing voices approach

- 2.1 This is a way of working with people who hear voices that has been developed over the last 25 years in Europe and is now practiced in 23 countries across the world. The hearing voices approach (also known as the Maastricht approach) was first developed in Maastricht, in the Netherlands by psychiatrist Marius Romme and researcher and science journalist Sandra Escher.
- 2.2 The hearing voices approach contends that people hearing voices can learn to cope with their voices and benefit from psychological and social interventions. It is based on three central tenets, that the phenomena of hearing voices is:
 - more prevalent in the general population than is generally understood by he mental health community,
 - A a personal reaction to life stresses, whose meaning or purpose can be deciphered and,
 - best considered a dissociative experience and not a psychotic symptom
- 2.3 The approach has become progressively more influential and has led to:
 - voice hearers organising themselves into networks, empowering themselves and working towards recovery in their own ways
 - services changing their policies and practice in respect to supporting people who hear voices by engaging the voice hearer about their experience and determining the meaning the voices have for them in relation to their lived experience, with the objective of developing long term coping strategies.
- 2.4 It can be realised via membership of peer support and self help groups and/or on a structured, one to one basis with mental health care workers.
- 2.5 It places a great emphasis on the development of an equal partnership between the voice hearer as an expert of their experience and the worker as an expert by profession working together to facilitate the recovery journey.

3. Redefining the meaning of voices

3.1 Research into hearing voices and other extreme experiences have shown that people hear voices and have other extreme experiences that are not in contact with psychiatric services and are not distressed by the experience. It is a common human experience with 2-6% of the population hearing voices on a regular basis.

In Y. Tien (1991) reported

Hallucinations are often manifestations of severe psychiatric conditions seen clinically. However, little is known is known about the distribution of incident hallucinations in the community, nor whether there has been a change over the past century. Data from the NIMH Epidemiologic Catchment Area Program is used here to provide descriptive information on the community distribution.

and Eaton (1991)

This analysis applies methods of screening to the problem of psychosis. A probability sample of 810 individuals from the Eastern Baltimore Mental Health Survey was interviewed in the self-report modality with the Diagnostic Interview Schedule and shortly thereafter by a psychiatrist. It is shown that a configuration of responses in the self-report modality can screen moderately well for psychosis, as measured by psychiatrists in the clinical modality.

In traditional Western psychiatry, hearing voices is often linked to psychiatric disorders, predominantly schizophrenia. Selection bias is responsible for this hundred-year-old distorted clinical view, because, until recently, psychiatrists didn't know about non-patient Voice Hearers in the community; treatment practice has been exclusively based on a disease model of hearing voices (Bentall, 2003).

The differences between the experienced characteristics of voices of non-patients, patients with dissociative experiences, and patients with a formal DSM-III and DSM-IV diagnosis of schizophrenia are non-specific (reviewed in Moskowitz & Corstens, in press).

- 3.4 In general, however, non-patients feel less powerless and are less afraid of their voices (Romme, 1992; Beavan, 2006). What makes Voice Hearing become patients is their reaction to their voices and the way they cope with the underlying problems that have evoked the voices (Romme, 1992). In their own research, Romme and Escher observed that, for 70% of the voice hearing patients and 50% of the non-patient VH, the onset of the voice hearing experience was clearly connected to threatening or traumatising daily life experiences (Romme, 1989). Similarly, for a group of 80 voice hearing children, 85% linked the start of the voices to trauma or stressful events, such as sexual and physical abuse, long-term emotional neglect, chronic bullying at school, loss of a loved one (and, often, being denied normal ways of bereavement), and parents' divorce (Escher, 2004). Many, however, were able to cope with their voices on their own, without needing professional treatment.
- 3.5 Demographic (epidemiological) research in the 1990's demonstrated that there were many people hearing voices in the general population (2% 6%) and were not necessarily troubled by them (Tien A.Y. (1991) *Distributions of hallucinations in the population* Social Psychiatry and Psychiatric Epidemiology, No.26, pp. 287 292 and Eaton W.W., Romanoski A., Anthony J.C., Nestadt G. (1991), *Screening for psychosis in the general population with a self report interview*, Journal of Nervous and Mental Disease, No. 179, pp 689 693). Only a small minority fulfilled the criteria for a psychiatric diagnosis and, of those, only a few seek psychiatric aid (Bijl, R.V., Ravelli, A. & Van Zessen, G. *Prevalence of psychotic disorder in the general population: results from the Netherlands mental health survey and incidence study.* Social Psychiatry & Epidemiology, 33, 587-596., 1998).
- 3.6 A recent study by <u>Lawrence C</u>, <u>Jones J</u>, <u>Cooper M</u>. <u>Lawrence C</u>, (2010) has reinforced these findings providing further supporting evidence:

This study provides details regarding demographic information and the experience of voice hearing from a fairly large sample of people who hear voices in a non-psychiatric population. It lends support to the idea that voice hearing occurs on a continuum, with evidence that many people hear voices in the general population and are not distressed by the experience.

As does a study by Michael Garrett, David Stone, Douglas Turkington (2009):

Individuals in random community samples not diagnosed as mentally ill report a variety of mental states along a continuum from 'normalcy' to psychosis. The existence of this continuum suggests that in addition to hallucinations and delusions, other more subtle reflections of psychotic thought processes might occur in ordinary mental life ... a questionnaire was administered to subjects in a random community sample to assess the frequency of the transient disruptions explored in the exercises in the general population. These disruptions appear to be quite common. This would suggest that at least some psychotic symptoms are a pathological expression of psychological processes latent in and widely distributed throughout the general population.

<u>Andrew Moskowitz</u> and <u>Dirk Corstens</u> (2008) go further in finding that there is no research evidence for the presumption that hearing voices are a psychotic symptom:

While auditory hallucinations are considered a core psychotic symptom, central to the diagnosis of schizophrenia, it has long been recognized that persons who are not psychotic may also hear voices. There is an entrenched clinical belief that distinctions can be made between these groups, typically, on the basis of the perceived location or the 'third-person' perspective of the voices. While it is generally believed that such characteristics of voices have significant clinical implications, and are important in the differential diagnosis between dissociative and psychotic disorders, there is no research evidence in support of this. Voices heard by persons diagnosed schizophrenic appear to be indistinguishable, on the basis of their experienced characteristics, from voices heard by persons with dissociative disorders or by persons with no mental disorder at all. On this and other bases outlined in this article, we argue that hearing voices should be considered a dissociative experience, which under some conditions may have pathological consequences. In other words, we believe that, while voices may occur in the context of a psychotic disorder, they should not be considered a psychotic symptom.

3.7 It is also of note that studies have found that hearing voices is not uncommon amongst mental health professionals as this study by Millham and Easton (1998) shows:

Seventy-nine nurses and student nurses working in the mental health field were asked to complete a questionnaire that asked about the prevalence of their experience of events that might be considered as examples of auditory hallucinations. Eighty-four per cent of the 55 nurses who returned the questionnaire described having experiences that might be described as auditory hallucinations. This level of prevalence is broadly consistent with other studies, and the difference between voices considered to indicate 'schizophrenia' and voices perceived as normal or unimportant is discussed. The relevance of these findings for the process of diagnosis and for the attitudes of nurses working in the mental health field towards voices reported by clients is highlighted.

And a similar study by Fleming M.P and Martin C.R (2009):

A defining summary feature of the psychiatric model is the distinctiveness of psychotic symptoms in those with a diagnosis of schizophrenia compared with non-clinical samples. The current study sought to challenge the prevailing psychiatric system by exploring the occurrence and experience of psychotic symptoms in mental health practitioners who routinely engage in therapeutic work with clients with a primary diagnosis of schizophrenia. A total of 16% (n = 19) of the sample indicated that they experienced voice hearing while 21% (n = 26) indicated they experienced delusions as assessed by validated assessment tools. The findings are indicative of a continuum model of psychotic symptom experience and run counter to the contemporary model of psychiatric classification of this disorder. The direction of future research is indicated.

4. The experiences of non-clinical and clinical voice hearers

4.1 <u>Sorrell E</u>, <u>Hayward M</u>, <u>Meddings S</u>.(2010) researched the differences between non-clinical and clinical voice hearers found non-clinical voice hearers regarded themselves as stronger than their voices and less distressed by them:

For clinical voice hearers, distress was significantly associated with perceptions of the voice as dominating and intrusive, and hearers distancing themselves from the voice. However, these associations were not independent of beliefs about voices' omnipotence or malevolence. Non-clinical voice hearers were significantly less distressed than clinical voice hearers and voices were perceived as less dominant, intrusive, malevolent and omnipotent. Non-clinical hearers were found to relate from a position of less distance to voices perceived as benevolent.

4.2 A second study in the same year by <u>Beavan V</u>, <u>Read J</u>. (2010) also studied subjects who heard voices from the general population and found that the more distressing the voice content the more likely the voice hearer was to have contact with mental health services:

The content of auditory hallucinations is sometimes dismissed as having little diagnostic/therapeutic importance. There is growing evidence that voice content may be crucial to understanding and working therapeutically with this experience. The aim of the present study is to explore, in a general population sample, the content and impact of voice-hearers' auditory hallucinations. A self-selected sample of 154 participants completed questionnaires about voice-hearing. A subsample of 50 participants completed semi-structured interviews. Participants experienced a range of voice content of high personal relevance,

with most experiencing both positive and negative content. Voice content was the only significant predictor of emotional distress and the strongest predictor of contact with mental health services. These findings suggest that content is an important characteristic of auditory hallucinations and should be explored with voice-hearers who find themselves in clinical settings.

4.3 These are important findings because it shows that the issue is not necessarily the fact of hearing voices in itself but the relationship between the voice hearer and their voices, further that voice hearers distressed by their experience can be helped to change their relationship with their voices and live with them successfully by better understanding the voice content.

As Lis-Bodil Karlsson (2008) reports:

... voice hearing can be such an overwhelming experience that it can even be experienced as 'more real than reality'. Voices are strong and powerful experiences that sometimes convey memories from the past or difficulties that the voice hearer would prefer to forget but in fact has had to confront. The voices also influence how the voice hearer sees his or her future.

Therefore we can see that talking to voice hearers about their voices, about their meaning and influence has become an issue of increasing concern to services, particularly in developing ways of assisting distressed voice hearers to understand their voices and in their recovery journeys.

5. Benefits of discussing the hearing voices experience:

- 5.1 Research and practice into understanding hearing voices has been undertaken over the last 25 years and there have been many in-depth research studies that have evaluated the benefits of discussing the hearing voices experience with people who hear voices and developing ways of working with them. This section considers the findings of this research in the following areas:
- 5.2 Voice-hearers want to discuss their voice experience: It would be beneficial for voice hearers if more opportunities to do so were provided by services and service workers. Workers can play an important part in assisting voice hearers to better understand their voices, however this is not the case for many services and practitioners.

For instance a study by Coffey M, Hewitt J. (2008) found that:

Voice hearers reported that interventions from community mental health nurses were limited to reviews of medication, access to the psychiatrist and non-directive counselling. They identified alternative needs, which involved talking more about the content and meaning of their voices. People who hear voices express an interest in more helpful responses from community mental health nurses..... The findings of this study indicate that nurses must begin to orientate themselves towards a more critical practice stance that encompasses available knowledge on the voice hearing experience.

England M. (2007) also found that:

Traditional views in nursing suggest that to engage voice hearers in a discussion of their voices is to support the psychopathology of the voice hearers. Research into how voice hearers conceptualize voice hearing has generated a range of perspectives, raising concerns about whether nurses capture sufficient, accurate and specific assessment data about the experiences of voice hearers.... Accurate and specific assessment of voice hearing may facilitate engagement with voice hearers and improve the selection of strategies to help them manage the voices that upset them.

5.3 It would be beneficial for mental health clinicians and other mental health workers to develop their knowledge about hearing voices (re. content, causation, coping strategies etc) and increase their skill set about how to work with and assist distressed voices hearers.

England M, Rubenstein L, Tripp-Reimer T (2003) reported that their study it was important to:

.... provide nurses with opportunities for discerning specific characteristics, antecedents, and consequences of voice hearing along with their implications for health and well-being. Discernment of this information will facilitate identification of more specific and meaningful options for helping voice hearers manage their voices.

Ritsher JB, Lucksted A, Otilingam PG, Grajales M. (2004) agreed:

We conclude that by offering a diversity of treatment options, eliciting patients' causal theories, and incorporating these into an individualized treatment strategy, clinicians are likely to help clients control the

distressing aspects of the voices, minimize stigma and discrimination, and make meaning of the experience.

Chin JT, Hayward M, Drinnan A. (2009) study concluded that:

... evidence that supports new developments in working relationally with voices. Working within this frame may help to emphasize hearers' strengths whilst ameliorating distress. However, this concept needs to be posed as a possible rather than an established conceptualization. (12)

Research by Jones M, Coffey M. (2011) provides further support for this:

People who hear voices make use of standard psychiatric explanations about the experience in their accounts. However, the accounts paint a more complex picture and show that people also impute personal meaning to the experience. This in turn implicates both personal and social identity; that is, how the person is known to themselves and to others. We suggest that this knowledge can inform a more thoughtful engagement with the experiences of voice hearing by mental health nurses. (13)

As does the research of Place C, Foxcroft R, Shaw J. (2011)

Working together, the nurse helps voice hearers construct a narrative that tells the story of their voices. Examples from the narratives show how they can help increase understanding of a person's voices, and how the mental health nurse in acute care can realistically offer therapeutic interventions that may help a person towards recovery. (14)

6. The value of hearing voices groups

6.1 Hearing Voice Groups have been running successfully for over twenty years, there are different kinds of groups. Peer-driven support groups, Self help groups run by workers, Limited session CBT groups, Skills-training groups, Mindfulness groups. The value to participants has been a focus of research.

The following studies are referenced in chapter 7 entitled "Hearing Voices Groups" from "Living with Voices – 50 Stories of Recovery" edited by Romme et al (15)

- 6.2 An early study by Pennings and Romme (1997) into how voice hearers appreciated talking with other voice hearer about their experiences found:
 - A It was easier to talk to other voice hearers than non-voice hearers
 - △ They recognised their own experiences in what others said especially negative effects
 - A majority of voice hearers accept their voices more after participating
 - A Changing ways of coping; accepting voices more; not doing what voices asked; being less impressed by what voices say; adopting a different attitude to the voices (not being afraid/understanding voices were related to things that had happened/were happening in their lives)
 - At beginning voices increased but this was managable
 - △ 80% would advise other Voice Hearers to take part in VHG's
- 6.3 There are also two studies by Julie Downs and the English Hearing Voices Network (2001, 2005) The 2001 study looked at the important factors in setting up successful groups including
 - Addressing planning issues (the importance of involving voice hearers in the planning and establishment of groups)
 - Appreciating the importance of the different ways of running groups; role of facilitator and responsibility issues (eg. Importance of role of staff members in learning a different way of supporting people)
- 6.4 The 2005 study asked voice hearer's why they attended groups. Results:
 - △ Opportunity to talk freely about voices and other sensations
 - △ To have experience accepted as real and not necessarily negative
 - ▲ To share ideas and coping strategies
 - ▲ To become less isolated
 - △ To no longer have to deny or keep quiet about the experience
 - ▲ To feel supported

- △ To be in a non-judgemental atmosphere
- ★ To gain positive reinforcement

6.5 A study by <u>Sara Maddings</u> et al. (2006) looked at social benefits (pre and post measurements) and found attending hearing voices groups:

- A Reduced isolation
- ♠ Feeling more socially confident
- A Increased self confidence and raised self esteem
- ▲ Less hospitalisation

Terry Conway (2006) Found that groups were:

- more effective when democratically structured
- where the voice hearers lead and take responsibility for direction of group and define it's purpose

Rebecca Morland (2003) considered the views of people hearing voices about the benefits and difficulties in attending groups and found:

- ▲ It encouraged and developed peoples ability to share experiences
- A Being there for each other was important
- Increased trust and disclosure becsame possible

7. Hearing voices groups have proven to be popular with voice hearers and the outcomes have been positive, as the following research shows:

Ruddle A, Mason O, Wykes T. (2011)

... Hearing Voices Groups (HVGs) are becoming increasingly common in both inpatient and outpatient settings. Where resources are constrained, HVGs are frequently viewed as a desirable alternative to individual therapy and are often preferred by service users themselves.... Successful groups supply a safe context for participants to share experiences, and enable dissemination of strategies for coping with voices as well as considering alternative beliefs about voices.

Sara Meddings, Linda Walley, Tracy Collins, Fay Tullett, Bruce McEwan and Kate Owen (2006), Their study quantified statistically significant improvements in participants' ability to live with and even control their voices, as well as collecting evidence of the qualitative benefits of knowing that others are also struggling with what can be a very isolating and alienating phenomenon.

Newton E, Larkin M, Melhuish R, Wykes T. (2007) found groups were appreciated by those attending: Voices groups' are appreciated by young people with auditory hallucinations, as sources of therapy, information, and support.

and

McLeod T, Morris M, Birchwood M, Dovey A. (2007)

Universality, the recognition that other people experience very similar problems, was one of the most beneficial factors of the intervention.

8. Hearing Voice Groups that use Cognitive Behavioral Therapy

CBT methodology have shown promising results and have been helpful for young people and adults:

Newton E, Landau S, Smith P, Monks P, Shergill S, Wykes T. (2005)

This study evaluates the effectiveness of group cognitive behavioral therapy (CBT) for young people with recent-onset auditory hallucinations (N=22), using a waiting list control. Outcome measures were administered at four separate time points. Significant reductions in auditory hallucinations occurred over the total treatment phase, but not over the waiting period. Further investigations in the form of randomized controlled trials are warranted.

McLeod T, Morris M, Birchwood M, Dovey A. (2007) also found CBT helpful:

The groups achieved a significant reduction in frequency of auditory hallucinations and in the beliefs about the power of the voice. Satisfaction measures also suggested that the group participants valued the

group and benefited from the structured sessions. Universality, the recognition that other people experience very similar problems, was one of the most beneficial factors of the intervention. This study suggests that group cognitive behavioural therapy was helpful in the treatment of auditory hallucinations.

and:

McLeod T, Morris M, Birchwood M, Dovey A. (2007) part 2

This second paper details the experience of the group and reports on the outcomes of the assessment measures. The study concludes that group CBT was helpful in the treatment of auditory hallucinations.

Further, a study by Penn DL, Meyer PS, Evans E, Wirth RJ, Cai K, Burchinal M.(2005) compared CBT to enhanced Supportive Therapy

Participants who received enhanced Supportive Therapy were less likely to both resist voices and to rate them as less malevolent through 12-month follow-up relative to participants who received CBT. Group CBT was associated with lower general and total symptom scores on the PANSS through 12-month-follow-up relative to participants who received enhanced ST. Outcomes improved through 12-month follow-up in both therapy groups, with enhanced ST having more specific impact on auditory hallucinations, and CBT impacting general psychotic symptoms.

Also:

Wykes T, Parr AM, Landau S. (1990)

Twenty-one DSM-IV diagnosed patients with schizophrenia with treatment-resistant, distressing auditory hallucinations were referred to a group programme consisting of six sessions of cognitive treatment following a strict protocol which emphasised individual power and control as well as coping strategies...There were significant changes in all three main outcome measures following treatment; those changes were maintained at follow-up and were greater than changes over the waiting-list period. Specifically, there were changes in perceived power and distress as well as increases in the number and effectiveness of the coping strategies.

9. One To one Work

Research into the use of a self help workbook intended to be used by voice hearers and partner workers also proved effective as this research shows:

Casstevens, J.W., Cohen D., Newman F.L., & Dumaine, M. (2006)

This pilot study employs a quasi-experimental pre-post design (n = 27) to evaluate the impact of a mentored self-help workbook (Coleman & Smith, 1997) intervention. Participants are diagnosed with severe and persistent mental disorders and experience medication-resistant psychotic symptoms. The cognitive-behaviorally based workbook is used to target improved self-management of affective and psychotic symptoms. The intervention can be implemented in community mental health settings by staff with less training than specialized or licensed clinicians. Results show statistically significant improvement on the Brief Psychiatric Rating Scale factor for Anxious Depression.

10. Conclusions

These studies have concluded that talking to voice-hearers about voices; establishing safe places for people who hear voices to discuss their experiences are beneficial and have positive outcomes for voice hearers.

There is also growing evidence that engaging with voice hearers about their experience reduces anxiety and isolation, lessens hospital admissions & remissions and most significantly enables voice hearers to move on with their lives. Engagement has proved particularly effective in assisting people who hear voices who have not been responding to other forms of treatment and therapy.