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Do peer-support groups for voice-hearers work? A small scale study of Hearing Voices Network support groups in Australia

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ABSTRACT

Hearing Voices Network (HVN) support groups have proliferated in the last decade, with anecdotal evidence suggesting they contribute significantly to the recovery trajectory of the voice-hearer members who attend them. However, to date there remains little empirical research into the efficacy of these groups and the processes that might underpin their efficacy. This article describes a small project evaluating the HVN groups in the large Australian state of New South Wales. Twenty-nine group members completed questionnaires exploring self-reported recovery-related and clinical outcomes, aspects of group process, and the extent to which core HVN principles were promoted within the group. Results indicate that HVN groups are associated with reported improvements across a number of recovery-related outcomes including feeling less isolated and more skilled in being with others, having improved self-esteem, and having a better understanding of their voice experiences. Positive changes were also noted in outcomes that are more traditionally associated with clinical improvements, such as decreased need for emergency help and medication, and increased hope in personal recovery. Although this study is small and based on self-report, the findings are promising and contribute to the small but growing literature on peer-supported interventions for psychosis and psychotic-like experiences.

Introduction

The Hearing Voices Movement, and its offspring INTERVOICE and the Hearing Voices Networks (HVN), are now relatively well-known among academics and clinicians working in the area of psychosis. The movement has at its core a number of guiding principles that shape the philosophy and practice of its members. While they are not stated as an exact dictum in any one space, review of key HVN resources and publications (Dillon & Hornstein, 2013; \url{http://www.intervoiceonline.org/about-intervoice}; \url{http://voicesnsw.com.au/groups/group-guidelines}) suggests nine key principles: hearing voices is a normal human experience, validation and acceptance, social connection, understanding, coping skills, confidence, hope, self-esteem, and personal power.

There is strong support for the Hearing Voices Movement within the community, demonstrated by the proliferation of local HVN peer support groups in over 23 countries (Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014). Anecdotal evidence suggests that many people who hear voices and attend these groups report they find them useful, with significant improvements in recovery.
domains reported by many group members. However, to date, more objective analysis of the efficacy of these groups, as well as the contributing factors to such favourable reports, has been sparse.

One reason for this is that research into community-based peer-led initiatives poses its own unique challenges, including the inappropriateness of randomisation, blind control, and standardisation of intervention (Colella & King, 2004; Finn, Bishop, & Sparrow, 2007). Hearing Voices Groups (HVG) by definition are extremely varied. Although they are formed on shared experience, the setup, content and practice within each group is very different (Corstens et al., 2014). Further, HVGs are run in an open format, which encourages group members to come and go as their needs change (Dillon & Hornstein, 2013). Isolating the effects of the group from other potential confounding variables is problematic due to the large proportion of HVG members who at some time may have contact with mental health services, be on prescribed medication and/or be receiving other psychological or social interventions.

Even deciding which effects to research is contentious due to the differential emphasis placed on various possible outcome factors. For example, the dominant psychiatric paradigm emphasises reduction in psychotic symptoms (i.e. auditory hallucinations) and functional impairment in its evaluation of whether or not an intervention is effective. Within the peer support literature, however, mental health recovery is defined in much broader terms and emphasises getting on with the life one chooses for oneself, be it in the presence or absence of symptoms (Coleman, 2004). Voice-hearers themselves speak of recovery in diverse ways (de Jager et al., 2015).

Despite these challenges, a handful of useful evaluations of HVGs have been conducted, and their findings converge in a way to build the foundation of an evidence base that HVN groups work. To date, we were able to identify two unpublished quantitative studies, one from a peer support group in Western Australia (Bowyer, 2010) and one from a secure inpatient unit in the UK (Slater, 2010). There is one published mixed methods study from Surrey in the UK (Meddings, Walley, Collins, Tullett, & McEwan, 2006), and two published qualitative studies, one from the UK (Oakland & Berry, 2014), and one from New South Wales in Australia (Dos Santos & Beavan, 2015).

Based on the findings of these five studies, there is growing and consistent evidence to suggest that HVN groups are helpful, with all five studies reporting improvements for the group members. Strong support was found for increased self-confidence/empowerment and self-esteem, with all five studies reporting improvements in these areas. Four of the five studies reported reduced sense of isolation and increased understanding/acceptance of voice experiences. Fewer studies (two or three) reported on areas such as confidence to talk about voice experiences with others, confidence to cope with voices, hope, frequency of voices, and hospital admissions, but those that did reported favourable outcomes. There is evidence from one or two of the studies to suggest that HVGs may reduce the need for emergency help, decrease perceived omnipotency of voices, and facilitate return to work or study.

The three studies that included a qualitative component explored participants’ views on why the groups were helpful (Dos Santos & Beavan, 2015; Meddings et al., 2006; Oakland & Berry, 2014). Responses indicated the importance of sharing personal experience, sharing coping strategies, being socially inclusive, normalisation of voice experiences, and promoting the core HVN principles. This latter seems worthy of further exploration as it may help to elucidate whether there are aspects of HVGs that are fundamental to their success that go beyond the more general benefits of attending a peer-led self-help group.

This article presents some findings from a larger research project that comprised a formal evaluation of the processes and outcomes of the Hearing Voices Support Groups run under the banner of the New South Wales Hearing Voices Network (HVN-NSW). In Australia, each state has its own independent HVN, with the first Australian HVN established in Western Australia in 2005, and the New South Wales HVN established in 2008. At the time of the submission of this article, the HVN-NSW supported 23 HVGs across metropolitan Sydney and regional New South Wales.

The larger project evaluation included assessment of the experience of the groups from participant and facilitator perspectives, adherence of facilitators to the principles and processes prescribed by the training, outcomes (clinical and recovery-oriented) for participants who attend the groups, and quality of group facilitation. The findings from the qualitative component of the project have been published
elsewhere (Dos Santos & Beavan, 2015). Briefly summarised, those findings described positive changes in self-esteem and in participants’ relationships with their voices. They also highlighted the importance of the social connections fostered within the group and the value of sharing experiences, initially with other group members and eventually with people outside the group, such as friends, family members and mental health workers. The current article focuses on the survey findings with regard to processes and outcomes of the HVGs from group member perspectives.

**Method**

**Participants**

A total of 29 people completed the HVG member survey. They ranged in age from 21 to 79 years old, with an average of 41 years of age. There were slightly more women than men in the sample (57% versus 43%, respectively), with a broad range in terms of length of voice-hearing experience, from 1 month to 53 years. There was also a broad range in terms of HVG participation, from one month to 61 months, with an average of 19 months. Participants were recruited from a total of seven different group locations, with a good spread across metropolitan and regional areas.

**Measures**

Participants completed a questionnaire designed specifically for the purposes of this study, and based on the questionnaire used by Bowyer (2010). The pen-and-paper questionnaire included numeric and open-ended items and explored the following areas: Participant demographics, group location, finding out about the group, self-reported recovery-related outcomes, self-reported clinical outcomes, the most useful aspects of attending the HVG, the promotion of HVN principles in the group, and confidence to become a HVG co-facilitator.

Participants were asked to rate their level of endorsement for 10 recovery-related outcomes and 11 clinically relevant outcomes. These outcomes were selected for the questionnaire based on previous literature reporting on benefits of attending HVGs (Bowyer, 2010; Slater, 2010; Meddings et al., 2006; Oakland & Berry, 2014).

**Procedure**

Ethics for the study was granted by the Australian College of Applied Psychology Human Research Ethics Committee (ACAP HREC approval number 104081113). All HVG members were invited to participate in the study via information from their group facilitators. To participate, group members completed the questionnaire provided to them by the group facilitator in their own time and returned the completed questionnaire via a pre-paid envelope to the primary author. Participation in the study was entirely voluntary and confidential. Data was collected during the period January 2014 to October 2014.

**Analysis**

Results were entered into Excel and descriptive statistical analyses were performed on the quantitative data. Responses to open-end items were organised into themes.

**Results**

**Finding out about HVGs**

Approximately half of participants heard about the HVG from a professional (54%), with a smaller proportion hearing about it from another voice-hearer (14%) or friend (14%). Only one person reported
reading about it online. The remainder reported various sources of awareness of the group, including being given a flyer at a health centre and hearing about it at an information session.

**Outcomes of attending a HVG**

Figures 1 and 2 present reported recovery-related outcomes of attending the HVG. As can be seen in Figure 1, participants were asked whether things had improved, stayed the same or deteriorated across a number of recovery-related domains. The majority (75%) of members reported that they felt more understood, with about the same number indicating that they were less isolated (68%) and felt better about themselves (68%). A small majority (61%) agreed that they had a better understanding of voice-hearing. Around 4 in 10 (43%) participants agreed that they were better able to cope with their voices, with around a third (32%) reporting no change in coping. It is of note that only a small proportion (one or two people) reported a negative shift in their sense of isolation (7%), understanding of voice-hearing (7%), feeling about themselves (4%) and coping (4%).

![Figure 1. Recovery-related outcomes of attending the Hearing Voices Group (a).](image1)

![Figure 2. Recovery-related outcomes of attending the Hearing Voices Group (b).](image2)
In terms of improvements in quality of life domains, the majority of participants agreed that they were better at being with people (75%) and speaking about their voice-hearing experiences (75%) as a result of attending the HVG. Half (50%) agreed that they were better at doing things they liked. A smaller proportion (39%) reported becoming better at doing things they had to do. A few people (18%) reported becoming better at something else. This included changing their understanding of voice-hearing from perceiving it to be an illness to understanding it as a gift, being able to speak in groups, and being better at understanding themselves and sharing experiences with others.

Outcomes that are traditionally associated with clinical improvement were also assessed. These are presented in Figure 3. Most (68%) participants reported that it was completely or mostly true that they were feeling more hopeful about the future since attending an HVG. A small majority reported that they had fewer hospital admissions (61%) and needed less emergency help (57%), while a lower proportion said that they needed less support from others (43%). Participants gave mixed results regarding need for medication, with just over a third (37%) reporting that it was at least a little bit true that they needed less medication.

In terms of voice-specific changes, 39% of participants reported no decrease in the frequency of their voices and half the participants reporting hearing fewer voices to some degree. Just over half (58%) said it was completely/mostly true that they had developed insight into the links between their voice-hearing experiences and life events. In terms of changes in relationship with their voices, 57% participants reported it was completely or mostly true that they were less afraid of the voices, 43% felt that the voices were more positive, and 40% that they had less power.

Participants were invited to respond to the open-ended question: “What is especially important for you in participating in the group?” Their responses are presented in Table 1 below. Quotes were organised into the following four themes: 1) Sharing and feedback; 2) Support and understanding of relatedness; 3) Changes in relating to the voices; 4) Normalising of experiences.

As a final note in terms of outcomes, a useful indicator of whether HVG members found attending the group beneficial is whether or not they would recommend the HVG to others. In this study, 96% of participants said that they would, and only one person said they would not.

**The promotion of HVN principles in HVGs**

Participants were also asked to provide feedback about the extent to which some key principles of the Hearing Voices Network were promoted in their HVG. As can be seen in Figure 4, all principles appear to be integrated into the facilitation practices of the HVGs to some degree with only a couple
of reports of principles being not at all promoted within their group. This was the case for coping skills (4%), normalising the experience (11%), and self-esteem (7%).

The vast majority (89%) of participants agreed that their HVG promoted social connection at least quite a lot. In addition, a high level of endorsement was received for promotion of understanding (84%), coping skills (82%), confidence (82%), hope (79%), and validation (79%). Three-quarters of respondents reported that their HVG group promoted the principle that hearing voices is a normal human experience completely or quite a lot, while 72% felt that self-esteem was promoted and 66% endorsed promotion of personal power through the group.

Table 1. Descriptive responses regarding the most useful aspects of HVG membership.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing and feedback</td>
<td>To be able to share our weeks and know we all experience basically the same thing.</td>
</tr>
<tr>
<td></td>
<td>A chance to talk to others with similar experience and find inspiration.</td>
</tr>
<tr>
<td></td>
<td>Getting the week off my chest and having a good chat.</td>
</tr>
<tr>
<td></td>
<td>To learn more things with other people's experiences.</td>
</tr>
<tr>
<td>Support and understanding of relatedness</td>
<td>Contact with other voice-hearers.</td>
</tr>
<tr>
<td></td>
<td>Feeling less isolated, friendly atmosphere, empathic.</td>
</tr>
<tr>
<td></td>
<td>People who understand me.</td>
</tr>
<tr>
<td></td>
<td>Talking with people with similar experiences. I feel less isolated. There is only so much a clinician can do for you, or understand what it is like.</td>
</tr>
<tr>
<td></td>
<td>Being with those who have had similar experiences to me.</td>
</tr>
<tr>
<td></td>
<td>Getting to meet people that are going through similar things. Having support.</td>
</tr>
<tr>
<td></td>
<td>To feel a sense of belonging, encourage others with support and sharing lived experiences.</td>
</tr>
<tr>
<td>Changes in relating to the voices</td>
<td>Acknowledging voices.</td>
</tr>
<tr>
<td></td>
<td>It helps me with my voices, helps me mainly to take control of them.</td>
</tr>
<tr>
<td></td>
<td>Method to reduce distress/disturbing/fearful voices.</td>
</tr>
<tr>
<td>Normalising of experiences</td>
<td>Knowing my experiences are not abnormal.</td>
</tr>
<tr>
<td></td>
<td>A sense of belonging to a group that accepts hearing voices as a part of normal human experience.</td>
</tr>
</tbody>
</table>

Figure 4. HVN principles promoted by the HVG.
confidence to transition from being a group member to a group facilitator

A final item in the questionnaire asked participants to rate their confidence in transitioning from being a group member to a co-facilitator. About half of respondents indicated a low level of confidence, with 19% reporting as being unconfident and 41% reported only feeling a little bit confident. About a quarter (26%) of participants said that they had quite a lot of confidence, and a further 15% reported being completely confident.

Discussion

Promotion of the HVGs within the community

People hear about HVGs from a number of sources. It was useful to know that mental health professionals appear to be promoting the groups, which suggests that the reputation of the HVN-NSW is relatively positive among people who work with voice-hearers. This may in part be due to the free in-service presentations that the HVN-NSW provides on a regular basis, and suggests that more of these presentations may be warranted.

A surprising finding was that only one participant found out about HVGs online. The last few decades have seen increasing numbers of people use the internet as the default approach to searching for information, especially about sensitive topics (Lenhart, Purcell, Smith, & Zickuhr, 2010). For those voice hearers not connected with a mental health-related service, the HVN’s online presence may be of particular importance.

Recovery-related and Clinical outcomes

The vast majority of participants reported improvements across a number of recovery-related outcomes since joining their HVG, including feeling less isolated and more skilled in being with others, having improved self-esteem, and having a better understanding of their voice experiences and ability to share this understanding with others. A notably smaller percentage reported improvements in coping with their voices. This finding would be worth exploring further, as improved coping with voices (as opposed to eradication of voices) is a fundamental aim of the HVN approach.

For a set of groups that by definition do not have a clinical focus and are run by facilitators who often have no clinical training, and most of whom are unpaid volunteers, HVG members reported strong improvements in clinically relevant domains, attributable to HVG attendance. This has important implications for future funding applications, future promotion of the groups (particularly to the mental health professional workforce) and in contributing to the current academic literature on the HVN approach and on peer support groups more generally.

Some important improvements were reported relating specifically to the experience of hearing voices. For example, large numbers of participants reported hearing fewer voices, being less afraid of their voices, believing their voices had become less powerful, and experiencing their voices as more positive. Benefits appeared to be experienced in different ways by different people, but the overall finding was consistent in that the large majority of HVG attendees reported improvements in at least some clinical domains. There were very few reports of deterioration. Due to the nature of the groups and the potential for triggering of negative emotions through hearing of others’ experiences, and the fact that support is not provided outside of the group hours, it is significant that negative effects were reported as rare.

Participants reported that the groups gave them hope, which in turn may have a positive impact on suicide risk and symptoms of comorbid conditions such as depression (Chang, 2003; Range & Penton, 1994). Further, over a third of participants reported needing less medication since joining the group. This finding would be very interesting to follow up with a more objective measure. Standard practice in psychiatry is to prescribe antipsychotic medication to people with psychotic disorders, often on a permanent basis. However, for some people, such medication has little to no positive effect (Miyamoto,
Duncan, Marx, & Lieberman, 2005) and a significant amount of distressing side effects (Hashimoto et al., 2012). If attending an HVG group could support the reduction in the dose of medication and/or reduce an individual’s reliance on medication, this would indeed be a significant finding. Such changes would, of course, need buy-in from clinical services, so establishing more sound evidence in this regard is important.

Similarly, if a stronger evidence base were established in support of the improvements reported here for other critically relevant areas such as use of emergency services and hospital admissions, the argument could be made that HVGs may have a role in decreasing the overall burden on health care services. This in turn might have important policy implications, such as formal endorsement of the HVGs by health services and/or the integration of HVN principles into standard health care training and practice.

Promotion of the HVN-NSW principles within the HVGs

It was reassuring to note that HVG members reported that the key principles of the HVN-NSW were actively promoted in their groups. It may be that the emphasis on these principles and instruction on how to translate principles into practice covered in the facilitator training is paying off in terms of group content and process. It also suggests that the explicit promotion of these principles contributes in significant ways to the benefits reported by HVG members. The qualitative information provided in this report and in the Dos Santos and Beavan (2015) article demonstrates that factors such as having a safe space to discuss voice experiences in a non-pathological framework, empowerment, and hope in recovery make a meaningful difference to people’s experience of the HVG’s efficacy.

Transitioning from HVG member to HVG co-facilitator

The HVN-NSW acknowledges the role of lived experience as a key contributor to effective facilitation of the HVGs. Indeed, the HVGs are promoted as peer support groups, and as an ideal the HVN-NSW encourages all HVGs to aim towards having at least one co-facilitator be a self-identified voice-hearer. Further, transitioning from being a group member to becoming a co-facilitator has long been recognised as a potentially helpful move forward in a person’s recovery from distressing voice experiences. However, anecdotally, many HVG facilitators have noted resistance from group members to take on the role, or even aspects of the role. This reluctance was evident to some degree in the findings of this study, but not as great as expected.

The findings suggest that there may be a good number of current HVG members (up to 40%) who with the right degree and quality of encouragement or guidance from the current facilitators would be able to transition towards co-facilitation. Current facilitators might therefore need support and guidance themselves around effectively promoting such transitions. The HVN-NSW could support this process by developing a resource accessible online to assist a) members who are thinking about stepping into the role of co-facilitator and b) current facilitators who wish to support a member to transition. Such a resource would likely be of value also to other HVNs internationally.

Limitations and future research implications

This is a small scale study representing only about a third of the HVN-NSW HVGs, and an even smaller proportion of overall group members. Having anticipated that voluntary participation in these kinds of populations is commonly restricted for a number of reasons (Colella & King, 2004; Finn et al., 2007), we were careful to pitch the study to our members as an important step in the development of the HVN-NSW with potentially meaningful consequences. Despite this, recruitment was difficult and we recommend that future studies in this area might more actively promote the research through additional channels, such as the HVN-NSW website and social media. Better canvassing of all group members past and present might also allow for additional investigation into attrition rates and reasons for
non-attendance. Notwithstanding the small number of participants, the sample is relatively diverse across age, gender, metropolitan/regional location, and length of experience hearing voices.

The data on outcomes is based on self-report only. There is the potential for participants to inflate their rate of improvement for a number of reasons, including an overall general positive experience of being a HVG member or a desire to support the HVN by emphasising or exaggerating the positive. There is also the possibility of sample bias, in that people who have had a good experience of the groups may be more likely to respond to the call for voluntary participation. Future studies might use more objective measures, such as hospital notes for example, to add to the existing evidence that HVGs are related to clinically significant improvements. While this approach is less consistent with the ethos of the HVN, which allows people to define their own recovery (which may or may not be in terms of clinical functioning), objective empirical evidence is likely to be taken more seriously by funders, policy-makers, and clinicians.

**Conclusion**

This small piece of research presents some promising self-reported outcomes for members of the New South Wales HVGs. The overall findings of this study are encouraging in that the members who chose to participate reported varied but positive benefits of attendance. The dissemination of this information to the community of people who hear voices and their friends and families could help to inform potential members about possible benefits of attending an HVG.

The study provides a significant contribution towards better understanding the processes and outcomes relevant to the HVGs that come under the umbrella of the HVN-NSW, and also will provide important information and evidence relevant to HVNs internationally, and peer-support groups more generally. Research evidence is important for a number of reasons. Firstly, some people who hear voices encounter significant distress, stigma, and disempowerment, and deserve to have information about and access to the most up-to-date empirically supported interventions. Indeed, there is a growing acceptance that mental health clients have the right to make informed choices about their treatment preferences (Essock et al., 2003). Providing research-based evidence means that voice-hearers can make informed choices about their mental health.

Secondly, if the HVNs want to be endorsed by and potentially integrated into local and national policy and practice, they need to have demonstrated efficacy around benefits to voice-hearers. As Snooks et al. (2011) assert, “evaluation of community based initiatives is essential if policy and local practice are to be based on evidence about what works, and how” (p 2). A likely spin-off of gaining credibility is the potential for increased funding (Miller, Zweben, & Johnson, 2005), which would of course help the HVN community to expand and be even more accessible to those who need it.

Thirdly, some authors have argued for the development of clinical theoretical models that support and explain the psychological mechanisms underpinning the efficacy of self-help groups (Olson, Jason, Ferrari, & Hutcheson, 2005). In particular, it might be interesting to further investigate the link between specific HVN principles and group outcomes. One advantage of theoretical models would be their ability to facilitate the collaboration between the peer workforce and mental health professionals. They would also give credibility to the concept of peer support, which might in turn lead to enhanced collaboration between self-help groups, the mental health system, and academic researchers, something that is lacking in a number of countries still (Weingarten, 2012).

With further research from the HVN-NSW and other HVNs across Australia and internationally, we are hopeful that the growing evidence base will provide a platform for ongoing support of the Hearing Voices Movement and the Hearing Voices Approach.

**Disclosure statement**

No potential conflict of interest was reported by the author.
References


