

Assessing the Impact and Effectiveness of Hearing Voices Network Self-Help Groups

Eleanor Longden^{1,4} · John Read² · Jacqui Dillon³

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Abstract The Hearing Voices Network (HVN) is an influential service-user led organisation that promotes self-help as an important aspect of recovery. This study presents the first systematic assessment of the impact and effectiveness of HVN self-help groups. A customized 45-item questionnaire, the Hearing Voices Groups Survey, was sent to 62 groups affiliated with the English HVN. 101 responses were received. Group attendance was credited with a range of positive emotional, social and clinical outcomes. Aspects that were particularly valued included: opportunities to meet other voice hearers, provision of support that was unavailable elsewhere, and the group being a safe and confidential place to discuss difficult issues. Participants perceived HVN groups to facilitate recovery processes and to be an important resource for helping them cope with their experiences. Mental health professionals can use their expertise to support the successful running of these groups.

Keywords Group psychotherapy · Outpatient treatment · Psychosocial interventions · Psychotic disorders · Social functioning · Vocational rehabilitation

Introduction

The English Hearing Voices Network (HVN) is a psychiatric service-user/survivor led organisation that promotes the needs and perspectives of individuals who experience voice hearing (auditory verbal hallucinations). Established in Manchester in 1988, HVN developed from the work of social psychiatrist Marius Romme and researcher Sandra Escher (Romme and Escher 1993, 2000; Romme et al. 2009) who, in partnership with both patient and non-patient voice hearers, promoted an approach that emphasises accepting and making sense of the experience, providing frameworks for coping and recovery, and exploring the role of psychosocial adversity in voice onset and maintenance. Today there are similar networks in 31 countries, with the English HVN deemed “the international gateway” for the global Hearing Voices Movement (James 2001, p. 47). In addition to its influence on research agendas, clinical practice, and mental health advocacy (Corstens et al. 2014; Longden et al. 2013; Woods 2013), a central part of HVN’s work is the provision of self-help groups, also known as ‘hearing voices groups,’ which endeavour to offer safe and accepting spaces to share one’s experiences, exchange coping strategies, and develop a positive identity as someone who hears voices (Dillon and Hornstein 2013). In contrast to more mainstream treatment approaches and therapy groups HVN encourages a strongly user-led stance, in which voice hearers are considered to be experts by experience, attendance is informal and not time-limited, and in which all perspectives are respected as valid and there is no expectation to conform with any particular explanatory framework (e.g., psychological, biomedical, spiritual, paranormal). Voice cessation is not considered the most important index of success, as opposed to understanding and accepting the experience and developing more

✉ Eleanor Longden
Eleanor.Longden@gmw.nhs.uk

¹ Institute of Psychology, Health and Society, University of Liverpool, Liverpool, UK

² School of Psychology, University of East London, London, UK

³ National Hearing Voices Network, Sheffield, UK

⁴ Psychosis Research Unit, Greater Manchester Mental Health NHS Foundation Trust, Harrop House, Bury New Road, Prestwich, Manchester M25 3BL, UK

constructive relationships with the voices one hears (Dillon and Hornstein 2013; Dillon and Longden 2012). However, despite the global dissemination of the approach, there is currently no systematic published evaluations of how members experience these groups beyond a series of important but relatively small qualitative studies assessing the experience of group members (Dos Santos and Beavan 2015; Hendry 2011; Oakland and Berry 2015; Romme 2009) and facilitators (Jones et al. 2016). This is partly attributable to the “uneasy relationship” (Corstens et al. 2014, p. 289) between mainstream medical/social science research agendas and the HVN, in the sense that it identifies itself as a reformative social movement that privileges narrative and lived experience as a primary evidence source.

As such, the aim of the current study is to provide the first quantitative survey of HVN self-help groups in order to assess members’ perceptions of their impact and effectiveness. Owing to the exploratory nature of the study, we had no pre-specified hypotheses. However, analyses were run to determine whether self-reported satisfaction with groups varied according to: gender, number of meetings attended, duration of membership, and whether group facilitators were voice hearers or mental health professionals.

Method

Participants

Participants were 101 adult members of HVN-affiliated community based self-help groups who reported hearing voices, were able to read and write English, and were willing to give informed consent.

Materials

A self-report questionnaire, the Hearing Voices Groups Survey (HVGS), was designed specifically for the study and contained the following sections: demographic details (six items); group format (six items); participant experiences within the group (11 items); the impact of membership on life outside the group (12 items; seven social/occupational, five clinical); and the effect of the group on emotional wellbeing (five items). Items in the latter three sections were scored on a five-point Likert scale (strongly agree—strongly disagree; much more often—much less often). All items had a ‘does not apply to me’ option. Five qualitative items were also included, responses to which will be reported elsewhere.

Questionnaire items were selected on the basis of existing literature about the benefits of attending HVN groups (Dillon and Hornstein 2013; Dos Santos and Beavan 2015; Hendry 2011; Oakland and Berry 2015;

Romme 2009). The HVGS was piloted with four representatives from national HVNs: two voice hearers from the Danish and United States Networks, one psychologist from the French Hearing Voices Network, and a psychiatrist from Intervoice (The International Network for Training, Education and Research into Hearing Voices). Written feedback was used to gauge content and face validity; re-word items considered biased or leading; and to increase readability and accessibility.

Procedure

Contact details for 62 groups were obtained from the database of the English HVN. Only groups operating in the community (as opposed to inpatient, forensic, or secure psychiatric settings) were included. Group facilitators were first contacted by email, and subsequently provided with paper copies of study information sheets, consent forms, and questionnaires to distribute to members. To enhance response rates, pre-paid return envelopes were provided and all groups received a written reminder about the project 3 months after materials were first sent. Participants were also given the option to email their responses if preferred. Ethical approval was received from the Committee on Research Ethics at the University of Liverpool.

Analysis

All 28 items from the three subscales about the experience or impact of the groups were summed to derive a total satisfaction score, with negative items reverse scored. Comparison between individual items and the scale’s neutral midpoint were assessed with one-sample t-tests. Differences in total score according to gender and group facilitator were calculated using independent groups t-tests and the Kruskal–Wallis H-test (although the latter is a non-parametric test, mean scores are still reported to enhance comparability with other data). Pearson’s correlation coefficients were used to examine associations between total score and number of meetings attended; and between experiences within the groups and different social/occupational (e.g., relationship with family, ability to work or study), emotional (e.g., feeling more hopeful, feeling happier) and clinical (e.g., hospital admissions, incidence of self-injury) outcomes. Because of the large number of planned comparisons, alpha was set at a more stringent $p \leq .01$ level to reduce the likelihood of type 1 error. All analyses were conducted using SPSS v.21 for Windows. To minimise data entry errors, 30 questionnaires were selected at random for checking; data entry agreement was 98.62%.

Results

Completed questionnaires were received from 101 individuals (53 males, 47 females, 1 transgender; mean age 44.54 years, SD 11.31). Eighty-three respondents (82.2%) identified as White British and 90 (89.1%) had received a diagnosis of psychotic disorder.

Impact

Across the sample the mean total satisfaction score was 99.65 (SD 15.78; range 33–129; maximum possible score 140). Mean scores across the three questionnaire subscales were as follows: ‘Experiences within the group’ 44.43 (SD 7.28; range 8–55; maximum possible score 55); ‘Life outside the group’ 31.53 (SD 9.07; range 8–56; maximum possible score 60); and ‘How the group makes you feel’ 21.07 (SD 3.18; range 7–25; maximum possible score 25). The mean score across all individual items in the HVGS was significantly higher than the neutral midpoint [$t(100)=59.59$, $p=.001$]. When examining the subscales, mean scores for ‘Experiences within the group’ [$t(100)=57.16$, $p=.001$], ‘Life outside the group’ [$t(99)=31.44$, $p=.001$], and ‘How the group makes you feel’ [$t(100)=57.07$, $p=.001$] were also all significantly higher than the neutral midpoint.

With the exception of whether participants found the group distressing at times, and whether the group had affected medication use, all individual item means were significantly different from the neutral midpoint (all p 's=0.001). All mean scores for negative statements were closest to ‘disagree.’ No positive statements had a mean score lower than ‘agree.’ Positive statements with the highest mean scores were: (1) that it is useful to meet other voice hearers in the group; (2) that groups provide support around voice hearing that is unavailable elsewhere; and (3) that groups feel like a safe and confidential place to discuss difficult things. Participants also credited the group with helping them improve a range of social, clinical and emotional variables (all p 's=0.001) with the exception of medication use, for which group attendance made ‘no difference’ on average ($p=.109$).

Group Comparisons

There were no significant differences in total scores between women ($M=97.74$; SD 15.72) and men ($M=95.72$; SD 15.98; $t(98)=-0.64$, $p=.525$). There were also no significant differences in satisfaction between groups that had only voice hearers as facilitators ($N=23$; $M=94.96$; SD 11.82), only mental health professionals as facilitators ($N=14$; $M=101.86$; SD 8.77), or voice hearers and professionals co-facilitating ($N=46$; $M=98.57$; SD 19.14; $\chi^2(2)=2.88$, $p=.236$).

There was a weak positive association between total score and number of meetings attended, which was not significant ($r=.13$, $p=.323$). Differences in total score were then examined according to length of membership (as only three individuals had attended for less than a month, this group was excluded from the analysis). There were no significant differences in satisfaction amongst respondents who had been coming to a group for 1–6 months ($M=96.71$; SD 12.33), 6 months–1 year ($M=97.39$; SD 12.49), 1–2 years ($M=91.63$; SD 19.73), or more than 2 years ($M=99.65$; SD 15.84; $\chi^2(3)=1.81$, $p=.613$).

Associations Between Group Experiences and Outcome

To explore possible processes and mechanisms of change, scores for ‘experiences within the group’ (11 items) were correlated with items for each remaining subscale: social/occupational (seven items) and clinical (five items) factors, and emotional wellbeing (five items).

There were numerous significant positive correlations between experiences within the group and positive social/occupational outcomes outside the group. The four items with the largest number of associations were: “The group has helped me feel less distressed by my voices,” “The group gives me support around voice hearing that I couldn’t get elsewhere,” “The group has given me helpful information about making sense of my voice hearing experiences” and “The group gives me positive messages about recovering from mental health problems,” which were all correlated with making more friends, feeling more confident in social situations, feeling more confident about being in work and/or study, feeling more confident about asking for help when needed, and developing a more positive relationship with one’s family. The strongest specific associations were between (1) “The group feels like a safe and confidential place to talk about difficult things” ($r=.59$, $p=.0001$) and “The group has helped me to cope with my voices” ($r=.59$, $p=.0001$) with feeling more confident about asking for help when needed; and (2) “The group has given me helpful information about making sense of my voice hearing experiences” ($r=.58$, $p=.0001$) and “The group has helped me to cope with my voices” ($r=.56$, $p=.0001$) with feeling more confident in social situations.

There were no significant positive associations between group experiences and the clinical variables, although “The group has been unhelpful for me” was negatively associated with reduced alcohol use ($r=-.47$, $p=.002$) and reduced self-injury ($r=-.59$, $p=.001$).

Five items were significantly associated with all the emotional wellbeing variables: “The group has helped me feel less distressed by my voices,” “The group has helped me feel more positive about being someone who hears voices,” “The group has given me helpful information about making

sense of my voice hearing experiences,” “The group has helped me to cope with my voices,” and “The group feels like a safe and confidential place to talk about difficult things.” The strongest associations were between feeling better about oneself and “The group has helped me feel less distressed by my voices” ($r = .57, p = .0001$) as well as “The group has helped me to cope with my voices” ($r = .58, p = .0001$); and “The group has helped me to cope with my voices” and feeling more hopeful ($r = .51, p = .0001$).

Discussion

Our results show that individuals with a diagnosis of psychosis/schizophrenia who have heard voices for many years can derive various benefits from attending HVN groups. Given that around a third of participants (34.6%) reported finding the group distressing at times, these gains still appear attainable despite the inherent difficulties in discussing the painful issues that are often related to hearing voices. Indeed, for some group members it may have been partly because there was a chance to talk about distressing material, without being judged or pathologised, that was beneficial. Furthermore this positive impact appears to occur promptly, with no significant differences in overall satisfaction according to membership duration. In addition to coping with voice hearing itself, groups were also credited with helping to improve a variety of social, emotional, and clinical outcomes, as well as providing a safe communal space in which to share experiences and meet others who have endured similar difficulties. In this respect it is notable that while 96 respondents (95%) reported mental health service use, one of the three most strongly endorsed items was that the group provided support that was unavailable elsewhere.

The current study complements and extends existing qualitative work on the benefits conferred by attending HVN groups. This includes an important observation made by Romme and Escher (1993) in some of their earliest work, and which in turn acted as a major impetus for the founding of the international Hearing Voices Movement: that many distressed individuals find it extremely valuable to meet with other people who hear voices. This process is referred to in various ways within the HVN literature: a “safe-haven” (Downs 2005, p. 5); “mutual acceptance through shared experience” (Hendry 2011, p. 76), and “the veil being lifted” (Oakland and Berry 2015, p. 123), and is powerfully described by one young woman with experience of group participation in the following way: “Creating a ‘fellowship’ around voice hearing gives the experience the recognition, the weight of reality, the value, that it truly has to every voice hearer” (quoted in Romme et al. 2009, p. 82). The concept of acceptance—both of voices

themselves, as well as one’s identity as a voice hearer—is a key tenet of the HVN approach (Romme and Escher 1993), and it is intuitive that providing a safe, communal forum in which individuals assemble to share coping strategies, validate one another’s stories, and exchange wisdom and insights, can reduce shame and isolation and expedite a greater sense of acceptance for an experience that is both distressing and highly stigmatized.

In turn, qualitative research into HVN groups suggests that acceptance of the voice hearing experience can facilitate social and self-acceptance (Hendry 2011; Oakland and Berry 2015; Romme 2009). In addition to clinical recovery and voice alleviation, psychosocial recovery has always been an instrumental component of the HVN approach; indeed, one does not necessarily preclude the other, and the Network has always emphasized the potential of leading a fulfilling and high-functioning life as someone who hears voices (Romme et al. 2009). With the exception of medication use, our study showed that individuals credited the group with helping improve every named outcome on the ‘life outside the group’ subscale, with every item pertaining to emotional wellbeing likewise positively endorsed. While our data do not permit firm conclusions about the exact nature of reported associations between group attendance and enhanced quality of life, they serve to highlight the importance of holistic approaches to recovery that acknowledge domains beyond the purely clinical and symptomatic. In this respect, although there was significant agreement that groups were helpful for coping with voices, items specifically related to voice hearing were not amongst the most strongly endorsed items. In turn while research into group CBT for voices is not strongly suggestive for reducing voice intensity or frequency, there is greater evidence of benefit in terms of enhanced self-esteem, social functioning, coping, and hopefulness (Barrowclough et al. 2006; Goodliffe et al. 2010; Wykes et al. 2005).

Although ‘self-help’ is often used interchangeably with ‘peer-support,’ both formats can include professional facilitation. The HVN’s Group Charter emphasizes the importance of ownership (in the sense that groups are survivor-led, retain a focus on self-help as opposed to treatment, and allow the philosophy and purpose of the group to be defined by members themselves), although it is also recognised that this is something non-voice hearers can assist with (Dillon and Longden 2012). While this can include the provision of practical resources and infrastructure, our findings also show the positive effect of interpersonal input from mental health professionals as group facilitators or co-facilitators. This in turn is consistent with the ethos of the Hearing Voices Movement, which has always emphasized the importance of developing positive alliance, partnership and cooperation between experts by experience (voice hearers and their families) and experts by profession

(mental health professionals and academics: Longden et al. 2013). We suggest there is a clear rationale for raising awareness of HVN groups amongst healthcare workers, both in terms of promoting group attendance for their own clients and/or exploring opportunities to support existing groups or establish new ones. Collaborating in a group setting may help professionals gain knowledge and confidence for supporting voice hearers (Jones et al. 2016), as well as enhance and inform their practice with the survivor-led and social psychiatric philosophies embedded within the HVN approach (Corstens et al. 2014). In turn, the strong user-led stance of HVN groups can be an appealing inducement for offering additional support to service-users who are disillusioned with mainstream psychiatric provision (Oakland and Berry 2015), or for whom available pharmacological or psychological treatments have been ineffective.

In summary there is a strong rationale for further research into HVN groups. However, consistent with the Network's emphasis on lived experience, it is important that such investigations avoid "clinicalization" (Jones et al. 2016, p. 116) by emphasizing outcomes that voice hearers themselves value and identify as relevant. As such, standardized measures of clinical recovery should be augmented with attempts to understand psychosocial factors, as well as the broader socio-political issues of identity, citizenship, wellbeing, and empowerment which are intrinsic to the HVN approach (Corstens et al. 2014). Specifically this should include studies, like the current one, which do not emphasize efficacy at the expense of examining mechanisms and pathways for change.

There were several limitations to the study, including its cross-sectional, observational design and the self-selected sample. Although the range of scores indicates that individuals who were critical of the groups were also motivated to respond, the study was unable to access the views of those who may have been sufficiently dissatisfied or disinterested to stop attending after one or two meetings. An additional limitation, given the international nature of the Hearing Voices Movement, is that the focus on English groups may limit the generalizability of the findings to other countries and cultures. Finally, although questions relating to social, emotional and clinical gains were prefaced "Because of the group..." it is not possible to directly infer a causal relationship between group attendance and outcome.

Compliance with Ethical Standards

Ethical Approval Ethical approval was received from the Committee on Research Ethics at the University of Liverpool and all participants provided written consent. Funding for this study was received from the Hearing the Voice project at the University of Durham, which is funded by a Wellcome Trust Strategic Award. Jacqui Dillon and Eleanor Longden have a non-financial professional association with the Hearing Voices Network and Jacqui Dillon provides paid training on facilitating and supporting hearing voices groups.

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