

Associations of collective self-help activity, health literacy and quality of life in patients with tinnitus



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ABSTRACT

Objective: About 800 of the 13,000 members of the German Tinnitus Association (DTL) are active in self-help groups (SHGs). This study analyzes whether SHG-participation is associated with tinnitus-related Health Literacy (HLit) and Quality of Life (QoL).

Methods: In a cross-sectional study 1108 tinnitus patients in- and outside of SHGs administered a questionnaire containing tinnitus-related burden, QoL, tinnitus knowledge, self-management, assessment of SHGs, and socio-demographics. Participants were divided into four subgroups: (1) active SHG-members (19.6%), (2) former SHG-members (10.6%), (3) DTL-members, but not in SHG (57.9%), (4) neither DTL- nor SHG-members (11.9%).

Results: Participant were 59.7% male and 61.3 years on average. SHG-attendees are on average 5 years older than non-attendees, and have a lower education, while there are no differences in gender-distribution. Regression analyses show significant associations between SHG-participation and tinnitus knowledge, coping and self-esteem. QoL, however, is not associated with SHG-participation. SHG-members report considerable further benefits from SHG-membership.

Conclusions: Despite the limitations through the cross-sectional design, it seems more likely that tinnitus-related HLit and other benefits are a result of SHG-participation than vice versa.

Practice implications: Health care providers should inform their patients about SHGs and encourage them to consider a SHG as a possible option for their self-management.

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1. Introduction

1.1. Tinnitus

Tinnitus describes the conscious perception of an auditory sensation in the absence of an external stimulus [1]. Besides the commonly described “ringing in the ears”, it also can sound like roaring, clicking, hissing, or buzzing [2]. It may be soft or loud, high- or low-pitched, in one ear or both ears. Tinnitus is a symptom that can result from various causes. A common cause is noise-induced hearing loss. Other triggers are ear infections, disease of the heart or blood vessels, Ménière's disease, brain tumors, emotional stress, exposure to certain medications, hormonal changes in women, thyroid abnormalities, and also temporary causes like earwax blocking the ear canal [3,4]. In most cases, however, an objective cause cannot be found, and a favored theory is locating the origin in the brain as kind of phantom perception [5]. This phenomenon is described as idiopathic tinnitus [6,7].

Langguth et al. [8] report that about 10–15% of people are affected, and for 10–20% of them their tinnitus is a serious and burdening problem, often leading to depression, anxiety or disturbed concentration. Prevalence in men and women is similar [9]. In Germany, around 10% of the adult population are experiencing an ongoing tinnitus for more than three months at the point of interview [10]. Due to a representative study 20 years ago, about 800,000 German citizens (1% of the population) were severely affected and in need of treatment [11].

1.2. The German Tinnitus Association

The German Tinnitus Association (Deutsche Tinnitus-Liga – DTL) is one of around 300 national self-help organizations (SHO) in Germany (SHO ≈ patient organization, health consumer organization). About 800 of their 13,000 members are actively participating in regional tinnitus self-help groups (SHGs). While the general aim of the DTL is to support their members by providing them with up-to-date information about medical, psychological and legal issues around tinnitus and morbus Ménière, it specifically supports the SHGs through training programs for their spokespersons to

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promote the quality of SHG-work and to enhance secondary and tertiary prevention. Content of the trainings include: knowledge and competence in group dynamics, group organization and moderator skills, communication, conflict management, and further psychological techniques to promote the spokespersons' skills.

1.3. Effects and effectiveness of self-help groups

Studies on effects and effectiveness of SHGs are generally rare and most of the existing surveys are based on qualitative research methodology rather than quantitative designs [12]. The few systematic comparative studies face several methodological challenges:

- i) the heterogeneity of indications and topics;
- ii) different forms and concepts of SHGs;
- iii) a multifaceted taxonomy (SHG, patient group, peer support group, mutual aid group, pressure group, etc.); and;
- iv) SHGs are voluntary and self-determined, which impedes randomization.

Furthermore, the definition of outcomes is complicated and interspersed with several implications. The most important one is that most SHGs' self-defined aims are not clinical outcomes rather than psychosocial relief such as reducing uncertainty, feeling not alone, cope better with the relevant condition, increase self-esteem etc. SHG-members are usually not aiming at overcoming a disease or finding cure, but to cope better with daily life, despite their specific health condition [13].

One clear exception from this can be seen in the SHGs for addiction. Abstinence is a clear and measurable outcome. There are some prospective studies with alcoholics showing a moderate to high efficacy of SHGs [14].

The most comprehensive systematic review of the clinical effectiveness of self care support networks has been conducted by Woolacott et al. [12]. In summary, they concluded with a given (moderate) effectiveness of SHGs in psychosocial and clinical outcomes. However, in a number of studies in this review it remained unclear, whether the self-care support networks were mere lay groups (in the meaning of the definition of a SHG) or professionally guided.

Despite several studies dealing with concepts, functionality, potential benefits of and satisfaction with SHGs, there is limited knowledge about associations between group-participation and health, health literacy, coping and quality of life [15,13].

1.4. Health literacy

"Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health." [16]. Health literacy (HLit) is a term that is only gradually evolving in SHGs and SHOs as an aim of collective self-help activities. This is surprising insofar as the different dimensions of HLit like knowledge, self-management, system orientation, and interaction with health care professionals are clearly a desired and pursued outcome of collective self-help. Following the intense discourse around concepts and measurements of HLit [17–19] a comprehensive explanation can be seen in the construct overlap between HLit and "empowerment" – HLit is "a concept that is both new and old" [20]. Empowerment has been used for describing the central aim of SHGs and SHOs for decades. Part of the discussion about HLit is dealing with the question whether HLit would not just be a new term for empowerment, a "new wine in old bottles" [21].

As HLit is a multi-faceted construct, not all elements of HLit could be gathered in this study. In the following, the focus is centered on tinnitus-related knowledge, coping, and self-esteem.

This article addresses the following research questions:

- a) Do Tinnitus-SHG-members know more about tinnitus (definition, treatment, implications etc.), cope better with tinnitus, and have a higher quality of life than other people with tinnitus outside of SHGs and/or self-help networks?
- b) How do Tinnitus-SHG-members assess their group participation, and what kind of benefits or discomfort do they perceive?

2. Methods

The project started in 2012 with an explorative qualitative study with 26 participants (professional consultants who trained the spokesmen of the Tinnitus-SHG in psychological and communication skills, voluntary consultants of the DTL, spokespersons of the Tinnitus-SHG and SHG-members) [22,23]. Based on 26 semi-structured interviews and results from two prior DTL-studies in 2004 [24] and 2010 [25] we developed a questionnaire focusing on SHG-activities and the work of the DTL. Table 1 shows all dimensions of the questionnaire. Recruitment started in May 2013. Data collection ended in March 2014. The ethical approval was given by the Hamburg chamber of psychotherapists in July 1 st, 2013 (No. 10/2012 PT K-HH).

Tinnitus knowledge was measured with a test consisting of nine items to be answered with "correct", "incorrect" or "don't know" and four multiple choice questions with five answer categories plus "don't know". The index was calculated as the sum of correct answers, "don't know"-answers were set as zero. Cronbach's alpha is 0.631, which is hardly satisfying, but more or less typical for such knowledge tests. The single items can be found in Table A1 in the Appendix.

Questionnaires were sent to all 13,000 DTL-members as part of the DTL's periodical 'Tinnitus-Forum' with detailed information about the study and data protection. A reminder followed with the next issue of the periodical. Participation was either anonymously without giving any personal data than sex, age, occupation and region or, additionally, pseudonymized with their membership-number for the case to participate in an optional follow-up survey a few years later. Participants did not receive any incentives. The administration time for the questionnaire was about 22 min on average.

The participants could either use the paper-pencil version of the questionnaire and forward it in a free envelope directly to the

Table 1
Dimensions of the questionnaire.

Dimension	No. of items
Tinnitus-characteristics and treatment [24]	22
Tinnitus-severity (Mini-TQ 12) [26]	12
Depression (General Health Questionnaire - mental health) [27]	3
Physical and mental health (Short Form 12) [28]	12
Generic Quality of Life (WHOQOL-Bref, generic item self-assessed QoL) [29]	1
Tinnitus-related knowledge ^a	13
Attitudes towards health and coping ^a	12
Support by others ^a	12
Assessment of the DTL ^a	19
Assessment and meaning of SHG (perspective of non-members) ^a	7
Assessment, activities and meaning of SHG (perspective of members) ^a	20
Socio-demographics ^b	15

^a Own development.

^b Based on German statistical office standards.

Department of Medical Sociology in Hamburg, or they could complete an identical online-version of the questionnaire. Informed consent and agreement to participate was given by sending the questionnaires to the research center. Participants could contact the research center at any time by phone or e-mail. The majority (77%) used the 8-pages paper-pencil version.

986 DTL-members in total participated. As all DTL-members received the questionnaire as part of the 'Tinnitus-Forum' the response rate (8%) is poor. It turned out that many DTL-members do not open and read the journal. The better option of sending an individual letter, however, was not affordable.

In parallel, further persons with tinnitus were recruited during five public information events. Visitors were given the questionnaires and study information with a free return envelope as well as the internet-link for the online-version. 150 questionnaires were returned to the department (43% postal and 57% online). The total gross sample consists of 1136 participants.

Group comparisons with statistical tests and logistic regressions were carried out with SPSSTM version 22. 26 cases with missing data on sex and/or age were excluded, plus two more cases which could not be assigned to one of the four groups under study. Thus, the analyses are based on a total sample of 1108 cases.

3. Results

3.1. Sample description

The sample consists of 60.7% male persons; the average age being 61.3 years (SD = 12.0 years, range: 23–89 years). 80.8% of the participants were hearing their tinnitus permanently without interruption. 34.2% perceived the ear noise in a loudness drowning all other sound. Tinnitus burden – assessed with the Mini-TQ 12 [26] – was high: 26.4% were classified *very severe*, 21.3% *severe*, 26.3% *moderate*, and 26% *mild*.

217 participants (19.6%) were actively engaged in SHGs, 118 (10.6%) indicated that they were SHG-members in the past, 641

(57.9%) were members of the DTL, but never involved in SHGs, and 132 (11.9%) were neither member of the DTL nor a member of a SHG. Table 2 shows the socio-demographics and some tinnitus characteristics of the four sub-groups distinguished by the degree of self-help activity.

Additionally, the participants answered a list of 10 therapies, which they have used or not, like psychotherapy, psychosomatic inpatient treatment, tinnitus retraining therapy, hyperbaric oxygen therapy, infusion therapies etc. plus an option "other therapies". They were also asked which therapy on this list was most helpful for them, plus the item "none of these". 40.1% of the participants answered "none". The most helpful therapies were psychosomatic in-patient treatment (36.9% of all users) and other treatment (25.6% of all users), which was most often specified as autogenic training and progressive muscle relaxation. Former SHG-members made experience with at least 4.8 interventions on average, active SHG-members with at least 4.0, and DTL-members without SHG-participation with 3.9 interventions. Tinnitus patients without self-help experience, however, had only used 2.1 interventions so far. Table A1 in the Appendix shows the different treatments.

3.2. Do Tinnitus-SHG-members know more about tinnitus, cope better with tinnitus, and have a higher quality of life than other people with tinnitus outside of SHGs and/or self-help networks?

The following comparisons aim at the question, whether the differences shown in Table 2 are associated with self-help activity or grounded in other factors. The group-differences in *tinnitus knowledge* and *coping* are remarkable, on the other hand, no differences could be found in terms of *quality of life*. As these differences could be caused by socio-demographic characteristics, several multivariate analyses were conducted to control for these possible confounders. Because of missings in different confounder variables the N is slightly reduced to 978 and 980. The dependent variables are tinnitus knowledge, self-efficacy, coping and quality of life.

Table 2
Characteristics of tinnitus patients divided in four sub-groups of self-help activity.

	(1) Active SHG-member (n = 217)	(2) Former SHG-member (n = 118)	(3) DTL-member, no SHG (n = 641)	(4) Neither DTL-member, nor SHG (n = 132)	Total (N = 1108)	p
Sex (male)	59.0%	65.3%	60.7%	50.8%	59.7%	0.101 ^b
Age, Mean (SD)	65.3 (10.6)	65.1 (10.2)	60.5 (11.8)	55.5 (13.5)	61.3 (12.0)	<0.001 ^c
More than 10 years of school education or university	36.4%	42.7%	50.8%	51.5%	47.2%	0.002 ^b
Household equivalence income ^d , Mean (SD)	1853 € (872 €)	2120 € (1110 €)	2126 € (1019 €)	1897 € (929 €)	2046 € (999 €)	0.003 ^c
Living alone	20.5%	19.8%	18.1%	23.1%	19.3%	0.578 ^b
Mini-TQ 12-Score, (scale: 1 to 4; the higher, the more severe), Mean (SD)	2.49 (1.14)	2.62 (1.14)	2.36 (1.13)	2.89 (1.10)	2.48 (1.14)	<0.001 ^a
Tinnitus duration in years, Mean (SD)	17.7 (11.0)	22.8 (11.3)	15.5 (10.7)	10.1 (13.3)	16.0 (11.8)	<0.001 ^c
Hearing loss/impairment (on one or both sides)	63.6%	72.6%	54.7%	33.6%	55.8%	<0.001 ^b
Hearing aid (on one or both sides)	54.5%	52.1%	38.2%	16.8%	41.3%	<0.001 ^b
Tinnitus knowledge, (scale from 0 to 13; the higher, the better), Mean (SD)	6.75 (2.36)	6.23 (2.41)	5.81 (2.29)	4.09 (2.56)	5.84 (2.46)	<0.001 ^a
"I cope well with my Tinnitus" (1=agree to 5=disagree), Mean (SD)	2.68 (1.18)	3.09 (1.20)	2.83 (1.10)	3.07 (1.06)	2.85 (1.13)	0.002 ^a
Quality of Life, (WHOQOL 1=very poor to 5=very good) ^e , Mean (SD)	3.35 (0.79)	3.16 (0.93)	3.34 (0.82)	3.22 (0.80)	3.31 (0.83)	0.075 ^a

All significance values ≤ 0.05 in bold.

^a Kruskal-Wallis-Test.

^b Chi-Square-Test.

^c ANOVA.

^d The household equivalence income is calculated on the basis of the household net-income reflecting the household-size and -composition (1st adult times factor 1.0, second adult times factor 0.5, children times factor 0.3 each). The equivalence income describes the amount of money, which a member of the household would have, if he/she would be living alone.

^e "How would you rate your quality of life?" *very poor* - *poor* - *neither poor nor good* - *good* - *very good*.

Table 3Associations between tinnitus knowledge and socio-demographics and tinnitus burden – binary logistic regression, simultaneous (N = 980; R² = 0.116).

Dependent Variable = tinnitus knowledge (above average)	B	p	OR	95% CI of OR	
Age (over 60 years)	−0.587	0.000	0.556	0.419	0.738
Sex (female)	0.064	0.650	1.066	0.810	1.401
Education (more than ten years of school/university)	0.491	0.001	1.634	1.235	2.160
Equivalence income (above average)	−0.003	0.983	0.997	0.758	1.312
Tinnitus Burden (<i>severe or very severe</i>)	−0.289	0.038	0.749	0.570	0.984
(1) SHG-member (reference)					
(2) Former SHG-member	−0.294	0.263	0.746	0.446	1.246
(3) DTL-member, not in SHG	−0.837	0.000	0.433	0.298	0.629
(4) Neither DTL-member, nor in SHG	−1.935	0.000	0.144	0.085	0.245

All odds ratios with significance 0.05 in bold.

Table 4Associations between health care orientation and socio-demographics and tinnitus burden – binary logistic regression, simultaneous (N = 980; R² = 0.082).

Dependent Variable = “I always know how and where to get information and advice” ^a	B	p	OR	95% CI	
Age (over 60 years)	0.298	0.033	1.347	1.025	1.770
Sex (female)	−0.013	0.927	0.988	0.755	1.291
Education (more than ten years of school/university)	0.113	0.419	1.120	0.851	1.473
Equivalent income (above average)	0.134	0.331	1.143	0.873	1.496
Tinnitus Burden (<i>severe or very severe</i>)	−0.405	0.003	0.667	0.511	0.871
(1) SHG-member (reference)					
(2) Former SHG-member	0.094	0.717	1.098	0.662	1.823
(3) DTL-member, not in SHG	−0.501	0.006	0.606	0.425	0.864
(4) Neither DTL-member, nor in SHG	−1.341	0.000	0.261	0.157	0.435

All odds ratios with significance 0.05 in bold.

^a Agree or partly agree = 53.3%; neither-nor or partly disagree or disagree = 46.7%.**Table 5**Associations between coping and socio-demographics and tinnitus burden – binary logistic regression, simultaneous (N = 980; R² = 0.327).

Dependent Variable = “I cope well with my tinnitus” ^a	B	p	OR	95% CI of OR	
Age (over 60 years)	0.307	0.063	1.359	0.983	1.878
Sex (female)	−0.440	0.007	0.644	0.468	0.887
Education (more than ten years of school/university)	0.192	0.245	1.211	0.877	1.674
Equivalent income (above average)	0.236	0.148	1.266	0.920	1.742
Tinnitus Burden (<i>severe or very severe</i>)	−2.332	0.000	0.097	0.068	0.138
(1) SHG-member (reference)					
(2) Former SHG-member	−0.592	0.050	0.553	0.306	0.999
(3) DTL-member, not in SHG	−0.348	0.094	0.706	0.470	1.061
(4) Neither DTL-member, nor in SHG	−0.235	0.439	0.790	0.435	1.434

All odds ratios with significance 0.05 in bold.

^{aa} Agree or partly agree = 34.2%; neither-nor or partly disagree or disagree = 65.8%.

Table 3 shows the predictors for high or low tinnitus knowledge. People above 60 years had less tinnitus knowledge than younger persons, with no significant gender differences. A higher degree of education was associated with more tinnitus knowledge. Also the severity of tinnitus burden was associated with tinnitus knowledge: people with higher burden knew less about tinnitus. The strongest associations were between tinnitus knowledge and the degree of self-help-activity expressed in the four sub-groups (1) currently active SHG-member, (2) former active SHG-member, (3) member of the self-help organization DTL (but not in a SHG), and (4) without any self-help activity.

Next to indication-specific knowledge and self-care, system orientation and personal research capabilities are further specific and important dimensions of HLit. The participants were asked to assess the following statement: “I always know how and where to get information and advice”. The odds ratios in Table 4 indicate that higher age has a positive effect on knowing how and where to get help. With focus on the different dimensions of HLit, this is remarkable insofar, as higher age shows just the opposite tendency compared to tinnitus-knowledge as shown in Table 3, which is focusing on tinnitus knowledge rather than help seeking behaviour.

While the other socio-demographic indicators indicate no association, higher tinnitus burden shows a clear negative impact. People, who are not active in SHGs and/or self-help networks have a significantly reduced chance to know how and where to get information and advice.

The same procedure – with “coping” as the dependent variable – shows a strong association with perceived tinnitus burden (Table 5). This is not surprising as the degree of burden is partly influenced by coping and vice versa. The associations between coping and non-SHG-membership are given, whereas (nearly) not significant. Interestingly, gender is also an own predictor for coping. Men gave a more positive self-assessment of their coping capabilities than women.

As an integrated proxy-measurement of self-esteem and health literacy we provided the participants with the following statement: “All in all I know more about tinnitus than most doctors.” This item combines personal experience in health care with self-efficacy and self-confidence. In order to control for inadequate self-conviction, the following model was enhanced by the results of the tinnitus-knowledge-test. The associations between self-esteem and tinnitus knowledge or the level of self-help activity are strong.

Table 6Associations between self-esteem and socio-demographics, tinnitus knowledge and tinnitus burden – binary logistic regression, simultaneous (N = 980; R² = 0.171).

Dependent Variable = “All in all I know more about tinnitus than most doctors” ^a	B	p	OR	95% CI	
Age (over 60 years)	0.259	0.083	1.296	0.967	1.737
Sex (female)	0.011	0.940	1.011	0.760	1.345
Education (more than ten years of school/university)	−0.098	0.511	0.906	0.676	1.215
Equivalent income (above average)	−0.111	0.449	0.895	0.672	1.192
Tinnitus knowledge (above average)	0.769	0.000	2.157	1.620	2.872
Tinnitus Burden (severe or very severe)	0.060	0.681	1.062	0.798	1.414
(1) SHG-member (reference)					
(2) Former SHG-member	−0.164	0.588	0.849	0.468	1.538
(3) DTL-member, not in SHG	−0.956	0.000	0.384	0.252	0.585
(4) Neither DTL-member, nor in SHG	−2.044	0.000	0.129	0.074	0.228

All odds ratios with significance 0.05 in bold.

^a Agree or partly agree or neither-nor = 61.3%; partly disagree or disagree = 38.7%.**Table 7**Associations between QoL and socio-demographics, and tinnitus burden – binary logistic regression, simultaneous (N = 978; R² = 0.332).

Dependent Variable = Quality of Life (WHOQOL, single item, above average)	B	p	OR	95% CI	
Age (over 60 years)	0.011	0.946	1.011	0.738	1.384
Sex (female)	−0.282	0.071	0.754	0.555	1.025
Education (more than ten years of school/university)	−0.041	0.795	0.960	0.702	1.311
Equivalent income (above average)	0.343	0.028	1.409	1.038	1.914
Tinnitus Burden (severe or very severe)	−2.302	0.000	0.100	0.073	0.137
(1) SHG-member (reference)					
(2) Former SHG-member	−0.280	0.336	0.756	0.427	1.336
(3) DTL-member, not in SHG	0.035	0.862	1.036	0.695	1.545
(4) Neither DTL-member, nor in SHG	0.331	0.254	1.392	0.789	2.457

All odds ratios with significance 0.05 in bold.

Current and former SHG-members are far more confident than persons outside of SHGs as shown in Table 6.

Finally, Table 7 focuses on the associations with QoL on the basis of the WHOQOL-Bref single item “How would you rate your quality of life?”. The perceived tinnitus burden absorbs nearly all other predictors, likely due to a substantial construct overlap. Next to this, only above average income is linked to higher QoL. Self-help activities, however, do not have an impact on QoL measured with this item. The two subscales of the SF-12 “emotional” and “physical” did not reveal different results (not shown in the table).

3.3. How do Tinnitus-SHG-members assess their group participation, and what kind of benefits or discomfort do they perceive?

The active members of SHGs answered 20 questions about their SHG, of which 13 asked about perceived personal effects or benefits of their SHG-participation. Fig. 1 shows self-assessed effects on the members’ individual well-being as well as on psycho-social functions of the group, and on tinnitus-burden itself. Although the latter shows the lowest agreement of all aspects listed here, a positive approval of far more than half of the SHG-members seems considerably high.

Focusing on these positive assessments, it should not be ignored that tinnitus-patients, who a) clearly decided not to make use of SHGs, or those, who b) have visited a SHG in the past, but discontinued, have their own specific reasons for this. They were asked to name these reasons. While most of the first group (a) stated they would assess SHGs as meaningful and helpful, but would not need them – mostly because of good support by others –, some argued that SHG participation could worsen their problem.

The 118 former SHG-members (b) were requested to describe, why they have discontinued group participation. 109 of them gave free text answers. The most often mentioned reasons were the dissolution of the SHG or an own increasing immobility not allowing to visit the group anymore. Nearly a fourth assessed the SHG as not being helpful for them. A smaller part quoted their

condition had become worse because of the talks in the SHG or that they disliked the group consistency, or group dynamics, respectively. Table 8 contains the given answers in coded categories.

4. Discussion and conclusion

4.1. Discussion

Comparative studies, which analyze possible effects of SHG participation on HLit, or other psycho-social and/or health outcomes are very rare [13]. The same is even true for associations between SHG participation and such outcomes compared with people not making use of SHGs. One reason for the lack of such studies is the incompatibility of the concept of SHGs with the methodological requirements of RCTs. SHGs are defined as “voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. [...]” [30, p.9].

Katz’ and Bender’s comprehensive definition is essentially still up-to-date. This explains why in the context of comparative studies on SHGs there are various conceptual factors, which impede RCTs and make comparative studies challenging:

- 1) The core of SHGs is voluntary enrollment. SHGs cannot be prescribed to patients, and SHGs cannot be obligated to house any person sent to them.
- 2) SHGs are self-determined. Their members decide on their own about what and how they want to deal with their issues and topics. Regular professional guidance is a criterion of definitional exclusion. Even within a same area of indications, conditions or problems, SHGs can operate differently. Thus, SHGs would be very different from a standardized therapy by educated health care professionals in an RCT.

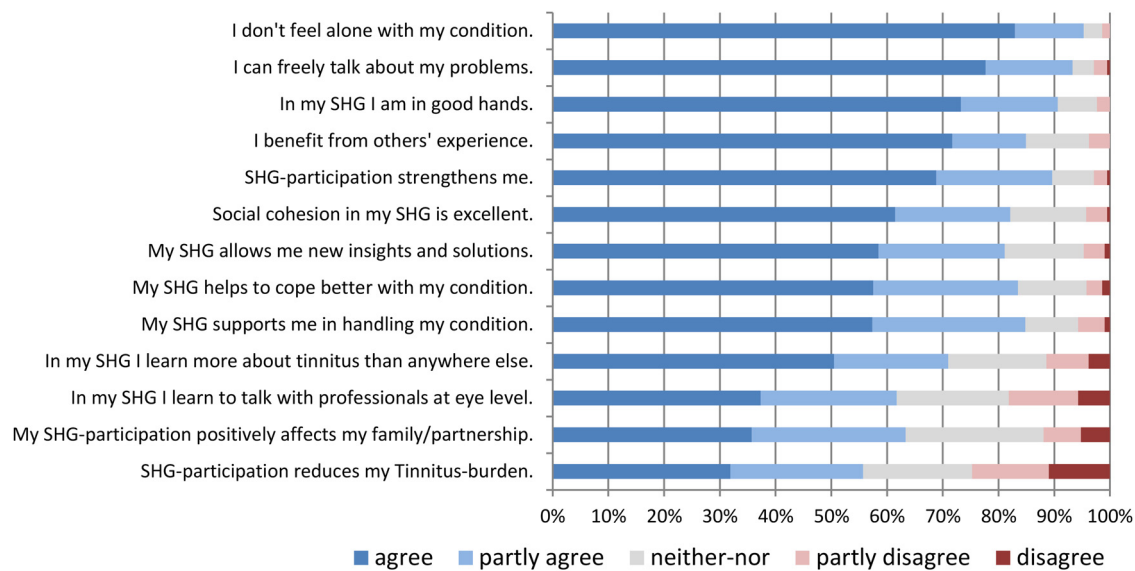


Fig. 1. Benefits of self-help-group participation from the view of active self-help-group members (In percent; N = 208–213).

Table 8

Reasons of former SHG-members to discontinue group-participation (N = 109).

Reasons, categorized free answers	%
Termination/dissolution of SHG	33.9
SHG not helpful	22.9
Decreased mobility/long distances	9.2
Felt uncomfortable with SHG	8.3
Other health related problems	7.3
Increased tinnitus burden through SHG	6.4
Interpersonal conflicts within SHG	6.4
Tinnitus compensated/no further need	5.5

- 3) SHGs are independent. They cannot be managed or controlled by other persons rather than themselves. They have no need to justify their dos and don'ts against others, and they are not in need to be evaluated by others.
- 4) SHGs are private and confidential. Many of them even anonymous.

Due to the cross-sectional design of this study, the focus is limited to associations rather than effects. Nevertheless, it seems more likely that a higher specific literacy is a result of self-help participation rather than vice versa, although we cannot rule out that patients with a higher literacy may have a higher probability to join a SHG. Concerning the other found associations like self-esteem or coping, it seems rather probable that persons with a pronounced self-esteem, broader openness and advanced coping capabilities have a higher disposition to join a SHG, which also could explain the differences in these aspects between SHG members and non-members.

However, if we look at the SHG members' self-assessment of perceived effects of self-help participation on coping, self-management, tinnitus-related knowledge, communication skills, social involvement, reduced burden of themselves and their families, reducing uncertainty and thus gaining security and capacities to act, we can consider these experience-based assessments as circumstantial evidence for the direction of causality from SHG participation towards health and psycho-social outcomes. It should be emphasized that psycho-social aspects like social cohesion and community in the framework of a common and shared problem predominate. A study by Wakefield et al. [31] showed that the level of subjective identification with a SHG (rather than the SHG-membership per se) can positively affect people's mental health. Concerning

tinnitus-SHG, talking about tinnitus and its related implications is only one of many topics in these peer-networks. Mutual aid, security and care in manifold aspects of daily life seem to work for most members in these "communities of fate" and thus may also have a positive influence on perceived tinnitus burden.

As mentioned in the introduction, SHGs of chronically ill usually do not aim to cure a disease rather than to learn living with it. This implies, however, that SHG-members share this idea. Tinnitus patients may look for cure and help for many years, so it seems very probable that hope for cure is also guiding them to a SHG. At the first moment some of them may feel disappointed when they realize that the other peers are not dealing with cure, but with their coping and emotional reactions towards a condition that will last for the rest of their life. This can be depressing, on the one hand. On the other hand, shared experiences of SHG-members have a high potential, specifically for new members, to become aware what is possible or impossible, what they can do, and what they better should not. Shifting from helplessness and unrealizable desires to gaining control and self-determination is probably one of the most important aspects of SHGs with respect to self-management.

It should also be discussed whether and to which extent other interventions and treatments are possibly influencing the found differences between the four groups. Former SHG-members experienced more treatment options than current SHG-members and DTL-members, while the patients without self-help experience have not even perceived half of them. It is possible that SHG participation stabilizes self-management skills learned in different care settings.

Comparing the four sub-groups divided into four levels of self-help activity from *no collective self-help activity* up to *current personal encounters in SHGs* we can see a kind of "self-help activity gradient". Based on the results, this gradient suggests: the higher the level of self-help activity, the greater the likelihood of having a higher HLit.

Talking with self-help representatives they often state that one motive for their commitment would be helping others to increase their QoL. Against this background the results on QoL must be disappointing. Similar results, however, could be found in other indication areas like multiple sclerosis, prostate cancer, diabetes mellitus or in family caregivers of persons with dementia [32]. QoL is a complex psychological multi-dimensional construct, which is determined by manifold factors in daily life, reaching from pain, job or family distress up to amorosness and joy. Therefore, it is probably just fair to ask, whether a SHG-meeting is able to overpower all these individual daily challenges and different feelings.

As SHG-membership is based on free choice, and as benevolent attitudes against self-help and regular participation are probably dependent of personal benefits, it is not surprising that the SHG-members' assessment of their perceived benefits is rather positive and may significantly be biased towards a positive evaluation. Nevertheless, we should acknowledge that the participants are reflecting what they think and believe.

4.2. Conclusion

SHGs can be “effective schools” for those affected in order to deal better with their condition. Quite remarkable is the fact that these activities are voluntary and self-determined. They relieve the professional health care system, though it is difficult to estimate possible economic effects in terms of saved or reduced health care costs and expenses. Arguing within this “economic logic”, however, we can suggest there is a high cost effectiveness – as long as the benefits of collective self-help are excelling potential harm. In other words, collective self-help does not cost nothing, but the 73 million Euros self-help support per year from the statutory health insurances in Germany is only 0.03 percent of their overall expenses. Although this is much more support and acknowledgement than in any other country in the world, this is still a very small percentage.

4.3. Limitations

None of the four sub-groups under study can be regarded as being representative for the whole group of tinnitus patients. All participants – even those who are not engaged in collective self-help at all – have in common that they are doing something for themselves and that they are interested in dealing with their disorder. Therefore, the whole sample may be biased towards a higher self-management and commitment compared to the basic population of all tinnitus patients.

Furthermore, due to the cross-sectional design we cannot rule out that the found differences might also be based on different personal characteristics influencing the decision to participate in a SHG or not. But as the results are controlled for socio-demographics, education and socio-economic status, the hypothesis that SHG-participation has an effect on the outcomes – rather than vice versa – seems much supported.

The questionnaire for this study was developed to cover as many dimensions as possible, but also had to be limited to eight pages and a maximum of 140 items. Some of them were reduced to single questions (e.g. coping, system orientation), and it can be contested whether these “proxy questions” are able to address the relevant dimension adequately.

4.4. Practice implications

Health care providers should inform their patients about SHGs and encourage them to consider whether a visit of a SHG might be a suitable option for them bearing the chance (not a guarantee) for better coping, self-management, and psycho-social relief.

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Conflict of interests

None.

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Appendix

See [Table A2](#).

Table A1

Use of tinnitus treatments divided in four sub-groups of self-help activity.

	(1) Active SHG-member (n = 216)	(2) Former SHG-member (n = 118)	(3) DTL-member, no SHG (n = 637)	(4) Neither DTL-member, nor SHG (n = 132)	Total ^a (N = 1103)	p (Chi-square)	Total n of use	Most helpful of all treatments ^a	Percentage of most helpful ^c
Infusion therapy (any)	67.1%	75.4%	68.8%	37.1%	65.4%	0.000	721	28	3.9%
Enhancing blood circulation (e.g. Ginkgo, pentoxifylline, . . .)	64.4%	76.3%	67.0%	51.5%	65.6%	0.000	724	6	0.8%
Hyperbaric oxygen therapy	13.0%	22.9%	19.0%	7.6%	16.9%	0.001	186	10	5.4%
Noiser	25.9%	33.9%	24.8%	14.4%	24.8%	0.004	273	34	12.5%
Acupuncture	43.5%	51.7%	42.9%	21.2%	41.3%	0.000	456	21	4.6%
Psychotherapy (group, out-patient care)	22.2%	31.4%	15.4%	5.3%	17.2%	0.000	190	16	8.4%
Psychotherapy (individual, out-patient care)	35.2%	39.8%	30.5%	16.7%	30.7%	0.000	339	54	15.9%
Tinnitus-retraining therapy	22.7%	22.9%	18.5%	8.3%	18.6%	0.005	205	47	22.9%
Psychosomatic unit (in-patient care)	39.8%	52.5%	38.9%	15.9%	37.8%	0.000	417	154	36.9%
Psychiatric unit (in-patient care)	6.5%	9.3%	5.8%	3.0%	6.0%	0.000	66	12	18.2%
Other treatments ^b	55.1%	63.6%	53.1%	29.5%	51.8%	0.000	571	146	25.6%

^a Missings = 5.

^b Most often specified as autogenic training and progressive muscle relaxation.

^c Percentage of *used* treatment that was assessed as being most helpful of all treatments used so far.

Table A2

Statements about tinnitus – correct or incorrect?

	correct	in- correct	don't know
1 Tinnitus is a symptom, not a disease.	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 By means of the quality of the ear noise (ringing, buzzing, hissing) the underlying disease can be diagnosed.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
3 Hardness of hearing is the most frequent cause of tinnitus.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
4 Tinnitus is more frequent in women rather than men.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
5 Tinnitus is frequently the precursor of a sudden hearing loss.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
6 The purpose of a tinnitus masker is to cover ear noise.	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 A Tinnitus deteriorates the hearing.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
8 High blood pressure and tinnitus are closely related.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
9 The efficacy of infusion therapy in acute tinnitus is scientifically evidenced.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

10 An acute tinnitus (t.) without an identifiable cause is called:

pathologic t. ☐ idiopathic t. ☒ reversible t. ☐ spontaneous t. ☐ reactive t. ☐ don't know ☐

11 If a tinnitus becomes burdening, we are talking about a tinnitus-...

composition ☐ decompensation ☒ sensation ☐ accumulation ☐ acculturation ☐ don't know ☐

12 A tinnitus is defined as chronic, if the ear noise...

... lasts for at least three months ☒ ... lasts for at least six months ☐ ... lasts for at least one year ☐ ... is perceived as very loud ☐ ... turns up and down ☐ don't know ☐

13 Who in the German health care system decides whether a therapy has to be covered by the statutory health insurance?

The German Federal Ministry of Health ☐ The German Federal Insurance Office ☐ Every health insurance company on its own ☐ The German Medical Association ☐ The Federal Joint Committee ☒ don't know ☐

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