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Choir singing and health status in people affected by cancer

Abstract

Cancer survival rates have improved dramatically over recent years, however health related quality of life (HRQoL) for many patients, survivors and their families remains low even after successful treatment. This mixed methods observational study explored the effects of participation in community choirs on HRQoL in individuals who have had cancer (patients) or have been affected by cancer (non-patients). This included a longitudinal analysis of choristers commencing the Tenovus Cancer Care 'Sing with Us' choirs across Wales and a series of semi-structured interviews and focus groups. Participants completed the Short-form 36 and the Hospital Anxiety and Depression Scale on commencement of the choir and 3 and 6 months later. On joining the choir, several domains of the SF36 were lower, indicating worse HRQoL and greater depression in patients than non-patients ($p < 0.05$). In patients, choir participation improved vitality, overall mental health and anxiety. In non-patients, choir participation improved anxiety ($p < 0.05$). Participants experienced the choirs as both an uplifting musical activity and a supportive community group. The results support the provision of a spectrum of support options to meet the different needs and preferences of people affected by cancer.

Keywords

Cancer, Choirs, Singing, Support groups

Introduction

Cancer survival rates have improved dramatically since the early 1990s, however quality of life for many patients, survivors and their families remains low even after successful treatment (Macmillan Cancer Support 2013). Patients often become anxious and depressed, experiencing changes to their sense of self and their social relationships (Middleton 2014). Following successful treatment many are left with long-term health problems as well as a fear of cancer reoccurrence (Macmillan Cancer Support 2013). Family members and informal carers may feel isolated, over-burdened, unsure of their role, and lacking in relevant knowledge (Coulson and Greenwood 2012, Hudson et al, 2002, Ream et al, 2013). Those who are bereaved may also find it difficult to adjust to their loss and experience loneliness (Lorenz 1998).

Support groups are one form of help available to people affected by cancer. These groups exist in a variety of forms including therapist-led, peer-led, online, face to face, and telephone groups (Hoey et al, 2008, Stephen et al, 2014). Typically they provide emotional support, opportunity for experience exchange between group members, cancer related information, access to wider networks, and practical support (Coulson and Greenwood 2012, Gottlieb and Wachala 2007). Cancer support groups have been linked to reduced anxiety and depression, a feeling of acceptance and belonging, a sense of hope and purpose, increased self-esteem, better adaptation to illness, increased confidence and sense of control, and improved quality of life (Ashing-Giwa et al, 2012, Ussher et al, 2006, Zabalequi et al, 2005). However research suggests that uptake of traditional support groups is low and that some individuals may prefer alternative styles of support (Bui et al, 2002, Pascoe et al, 2000, Sautier et al, 2014, Ussher et al, 2006).

This paper focuses on choirs as a novel form of support for people affected by cancer. A systematic mapping of research evidence identified 48 studies which focus on choir singing and wellbeing and identified benefits including relaxation, improved mood, increased confidence, and increased sense of community (Clift et al, 2010). There is evidence to suggest that choirs may benefit a range of clinical populations (Bannan and Montgomery-Smith 2008, Bonilha et al, 2009, Camic et al, 2011, Clift and Morrison 2011, Dingle et al, 2012, Kenny and Faunce 2004, Lesta and Petocz , Lord et al, 2010, Lord et al, 2012, Tamplin J et al, 2013). However, research around cancer and choir singing is limited. A systematic review of thirty trials found that a range of music interventions including active engagement in music may benefit cancer patients in terms of decreased anxiety and improved mood (Bradt et al, 2011). Additionally our pilot study suggested that singing can

contribute to improved quality of life, self-esteem and confidence (Gale et al, 2010).

The aim of this mixed-methods study was to examine whether choir singing provides support to individuals with a current or past diagnosis of cancer, and those affected by cancer in other ways (non-patients) including family, friends or carers. The objectives were to examine differences in health related quality of life (HRQoL) in patients with a current or past diagnosis of cancer and non-patients, and to explore if there was any difference in their response to a period of choir attendance. Subgroups of patients and non-patients were also interviewed and involved in focus groups to explore their experience of attending the choir. It was anticipated that there would be a difference in health status between patients and non-patients and that participation in the choir would have an effect on HRQoL.

Methods

Study Design

This mixed-methods observational study comprised two simultaneous phases: a longitudinal study of choristers commencing the Tenovus Cancer Care (Tenovus) 'Sing with Us' choir and a series of semi-structured interviews and focus groups with choir members across Wales. The study reflects a concurrent triangulation design (Creswell 2009) in that quantitative and qualitative data were collected concurrently, analysed separately and then compared.

'Sing with Us' involves community cancer support choirs set up and supported by Tenovus in 15 sites across Wales. **Tenovus is a charity, originating in Wales, which aims to provide support, advice and treatment to people affected by cancer.** The choirs are open to anyone affected by cancer including patients, survivors, and people affected by cancer in other ways such as relatives, carers or friends (termed non-patients), independent of previous musical experience. Recruitment of choir members is managed by Tenovus and aims to reach as far across the local community as possible including posters, flyers, newspaper advertisements, promotion at events, and family and friends evenings. The choir leaders are professional musicians, with rehearsals undertaken in a community setting for approximately 1.5 hrs per week. A typical rehearsal includes 30 minutes (optional) for social engagement and refreshments, 5 minutes for announcements, 10 minutes for warmups (vocal exercises usually with movement), and 45 minutes for singing (new and existing repertoire). Music performed is largely contemporary popular music with some traditional songs. The choirs perform frequently in their local areas and together as a mass choir on special occasions.

Recruitment of study participants from 'Sing with us' choirs was on a rolling basis with all

new choir members between March 2012 and October 2014 offered the opportunity to take part in the research and information sheets given to interested parties by choir organisers.

The initial 15 choirs were set up by Tenovus and supported for 3 years by a Big Lottery Grant. Since then the choirs have been funded by Tenovus.

Informed consent was obtained from all individual participants included in the study. Ethical approval was gained from the School of Healthcare Sciences Research and Development Ethics Committee at Cardiff University.

Quantitative assessments

The age and gender of study participants were recorded as well as how they were affected by cancer, and previous choir and musical experience. Participants were invited to self-complete questionnaires at the choir rehearsals as follows: initial (Q1, upon joining the choir), 3months (Q2) and 6months (Q3) post initial questionnaire. The following questionnaires were completed:

The RAND SF-36 questionnaire is a self-administered questionnaire which assesses multiple dimensions of HRQoL. It is a generic questionnaire which has been validated in a number of populations including cancer and can be used to compare healthy and pathological conditions (Bowling et al, 1999). The SF356 has established validity and reliability in a variety of populations(Ware Jr and Gandek 1998) and has demonstrated sensitivity in the pilot study in a similar population (Gale et al, 2010).

Higher scores indicate better HRQoL. Questionnaires were only included if a minimum of 33 questions of the SF-36 were complete, this ensures inclusion of questionnaires which were 80% complete. Data missing (i.e if 3 or less questions were incomplete) from the initial questionnaire were derived by imputation (Little's MCAR test: Chi-Square = 38.827, DF = 47, Sig. = .796).

The Hospital Anxiety and Depression (HAD) Scale is a self-rated widely used assessment tool for anxiety and depression in patients with both somatic and mental health problems valid for use in the community. It has as good sensitivity and specificity as other commonly used screening instruments (Zigmond and Snaith 1983). Normal HAD score is 0-7, the borderline HAD score is 8-10, and a high HAD score is 11-21.

Quantitative data were analysed using SPSS version 20. As data were not parametric, median interquartile range (IQR) are presented. Groups were compared using Kruskal

Wallace and Chi square test, as well as the Friedman test for repeated measures analysis.

Qualitative data

Participants were asked whether or not they wished to opt into the qualitative phase of the study (either interview or focus group) via tick boxes on the questionnaire. Purposive sampling was then used to identify a diverse sample of participants (patients, survivors, bereaved family members, carers, males and females) from across Wales (different regions as well as urban and rural locations). The sampling method aimed to provide access to a range of views from choir members who had been singing for three months or more. Interviews were conducted face to face or by telephone depending upon the participant's preference, lasted between 20 minutes to over an hour and were digitally recorded. Issues addressed in the interviews included impact of cancer on all aspects of life, cancer support, musical experience, motivations for joining Sing With Us, experience of Sing With Us, benefits of choir involvement, and dislikes or areas for change.

Additionally focus groups were undertaken with members of choirs in South, South West and North Wales. Focus groups were composed of a purposive-convenience sample of choir members from the three choirs (based on range of cancer-related experience and willingness to participate) and held in the usual choir rehearsal venues. Four questions based around motivation for choir singing, benefits, dislikes and future direction of the choirs were used to facilitate the group sessions. Prior to both interviews and focus groups, the interviewer (CR) made a conscious effort to build rapport between herself and the participant(s) and to establish a comfortable interview environment.

An attempt was also made to interview individuals who had dropped out of the choirs. Sing with Us provided a list of 20 former choir members who had agreed to be contacted for this purpose, however the majority did not return telephone calls/emails or stated that they were too busy to be interviewed. Consequently an online questionnaire based on the interview schedule was offered as an alternative. The interviews (and questionnaire) focused on reasons for leaving the choir as well as anything which participants enjoyed.

A systematic approach to analysis based on guidelines by Braun and Clarke (2006) was used to explore and categorise the data. Transcripts were coded line by line using NVivo software and grouped together to form themes. These were then reviewed and refined as more data became available. **Although data were coded as one set, constant comparisons were made between data extracts (for example between focus group and interview data and between participants), with particular attention to identifying group norms in the focus group data.** Finally a thematic map was created to indicate how themes related to one another.

The strength of a theme was determined by the number of participants and quotes alluding to that theme; thus it was possible to order themes into overarching themes, subthemes and standalone themes (Figure 1). Analysis occurred simultaneously with data collection with no new themes emerging after the first ten interviews, and themes deemed saturated by the thirtieth interview. The coding was 'checked' by inviting participants to comment on a textual summary of the analysis via email, confirming themes and yielding no changes.

Mixed methods analysis

Following separate analyses of the quantitative and qualitative data, the research team held several meetings to identify where and how the data converged and diverged (Fig 2). These discussions prompted several returns to the original data and additional analysis to answer questions posed by one data set on the other.

Results

Quantitative data

Thirteen new choirs which commenced between March 2012 and April 2014 were included in the present analysis. At this time the total population of adult attendees of all existing choirs was 1,652 (median age 57yrs [range: 18-95]). The number of study participants in each choir ranged from 25 (Llanelli) to 145 Cardiff (Table 1). The majority (85%) of choir participants were women in both patients and non-patient groups. Of the 1652, 382 (23%) were current or past cancer patients (230 survivors). Patients reported many different types of cancer; breast cancer was by far the largest category (119 in number); other categories were each less than 10 in number. In total 222 (27%) patients with past or present cancer and 593 non-patients completed an initial questionnaire. There was no difference in the past experience of choir singing reported by patients or non-patients, over 40% had no choir experience. Similarly there was no difference in musical background and over 50% had never played a musical instrument.

On joining the choir, patients were significantly older than non-patients and had lower HRQoL for all domains of the SF36, and greater depression than non-patients ($p < 0.05$) (Table 2). Patients showed no gender differences in any domains of the SF36 or HAD score, while in non-patients females reported significantly lower vitality: median (IQR) (69 (50-75)) and social function (88 (63-100)) than males: vitality (69 (50-75)) social function (100 (75-100); $p < 0.05$), although overall mental and physical health and HAD scores were not

different.

Of the study participants who reported having cancer, 63 were on current treatment, 27 were not on treatment, 32 were survivors on treatment and 100 were survivors not on treatment. There was no significant difference in overall mental health, anxiety or depression score; overall physical health score differed significantly between groups ($p < 0.05$). Median overall physical health score for patients on current treatment was 62 (44-79); for survivors on treatment 64 (52-79); for patients not on current treatment 71 (37-78); and for survivors not on current treatment 78 (60-90). Age related to overall physical health score in patients positively ($r = 0.163$) and non-patients negatively ($r = -0.226$). Age also related positively to overall mental health score in patients ($r = 0.167$) and non-patients ($r = 0.089$) (all $p < 0.05$). In addition age related negatively to anxiety score in patients ($r = -0.154$) and non-patients ($r = -0.149$) (all $p < 0.05$) but not depression score.

Attendance was high (70%) in both patients and non-patients (Table 2). Median membership duration, whilst individuals remained in the choir, in patients was 28 (7-65) weeks; 168 patients attended more than 50% of rehearsals. There was no significant difference in HRQoL between patients who attended more or less than 50% of rehearsals. In non-patients median membership duration was 25 (8-49) weeks; 495 individuals attended more than 50% or rehearsals. Non-patients attending less than 50% had a lower overall mental health score (76 (54-83)) and higher anxiety (8 (4-10)) and depression (4 (2-6)) scores, than those who attended more than 50%; overall mental health score (78 (61-88)), anxiety (8 (4-10)) and depression (4 (2-6)) score. Patients with lower attendance were younger; age was only weakly related to overall mental health score ($r = 0.089$, $p = 0.03$) and anxiety score ($r = -0.149$, $p < 0.01$).

Longitudinal quantitative data

Of the 816 study participants 60 patients (27%) and 143 non-patients (24%) completed initial, 3month and 6month questionnaires. The time between initial assessment and Q2 was median (IQR) 4 (3.5-4.4) and to Q3 was 7 (6.5-7.2) this interval did not differ between the groups ($p > 0.05$). Patients who only completed the initial questionnaire had lower overall physical and mental health scores and higher anxiety and depression scores (Table 3). Non-patients who only completed the initial questionnaire had greater anxiety and depression scores but no difference in HRQoL.

In patients who completed the 3month and 6month questionnaires vitality and overall mental health scores increased and levels of anxiety reduced significantly in both patients and non-

patients (Table 3).

Qualitative data

30 out of 40 potential participants agreed to participate in qualitative interviews. Of the 30 interviews recorded, one was unintelligible due to a technical error leaving 29 usable transcripts. Comparable to the overall choir demographic, five of 29 interviewees were male, median age 60 (IQR 55-65). Current occupations included teaching, health/social care work, management, administration and writing; however a large number of interviewees were retired (n=11). Thirteen participants were bereaved through cancer, 11 had received a diagnosis of cancer (at least 3 were receiving on-going treatment), three were family members and/or carers of patients with current cancer, 2 had chronic health conditions other than cancer, and 1 was a healthcare professional. Additionally, 20 choir members (people with cancer, cancer survivors, friends, family members and carers) were involved in three focus groups (n=4, 10 and 6 respectively; this difference in size reflects the degree of interest shown in each choir and turn out on the day). A further six out of 20 former choir members (two cancer survivors, three family members, one not stated) engaged in either interviews or online questionnaires. Reasons for non-response included illness, participants stating that they were too busy, or unknown (did not respond to contact by the research team).

The qualitative data were organised into eleven themes (Figure 1, Table 4; superscript references relate to Table 4). The overarching theme 'choir singing improves HRQoL' was linked to 3 primary themes: 'singing has a positive effect on HRQoL', 'choir community has a positive effect on HRQoL' and 'choir singing helps people to cope with cancer'. These three themes were strongly interrelated, reflecting participants' perceptions of choir singing as both a musical and social activity. There were also 7 subthemes relating to the main themes and 2 standalone themes around the effect of cancer on mood and reasons for disengaging from the choir.

All participants had been affected by cancer in some way, either as a patient, partner/spouse, family member, friend, carer or healthcare professional. Whilst participants differed in the degree to which they felt they had coped or were coping with cancer it was clear that the diagnosis had a profound effect on mood. Participants also spoke about the impact of cancer upon the whole family. Typically those with the diagnosis were portrayed as more able to cope than those around them ^[a]. Two participants also talked about the uncertainty of remission and the need for post-treatment support ^[b]. Prior to Sing with Us, the majority of participants (patients and non-patients) had drawn their support from internal sources such as spouses and other family members rather than traditional support groups.

The word 'uplifting' was used 23 times across the data set to describe choir singing ^[c]. Other phrases included 'lifts your spirit', 'gives you a boost', 'picks you up', and 'living in the moment'. When asked, 'what is it about singing that lifts your mood?' participants often referred to harmonies and song lyrics which they described as powerful and motivating ^[d]. Participants also suggested that improvement in mood was not confined to rehearsals or performances, but lasted throughout the week. This was enhanced by learning and listening to the music (available on CDs) between rehearsals ^[e]. Although participants were quicker to point out improvements in mood than physical health, some physical health improvements were noted. Five participants spoke about the relaxing effect of singing. Four reported improvements in breathing and five felt improved levels of fatigue. One participant also felt that singing and learning music had helped to improve his memory, specifically name recall.

Participants typically spoke about the choirs as both a singing and social experience. Eighteen participants emphasised the value of being with people in the choir who had been through or were going through similar cancer-related experiences ^[f]. Although 15 participants described the choirs as a 'family', this did not necessarily mean having a close relationship with everyone in the group. Rather they emphasised a supportive environment amongst people who had gone through or were going through similar experiences ^[g] (interestingly, whilst there were no distinct differences between interview and focus group data, the 'family' analogy was particularly emphasised in the latter with agreement between group members). Three interview participants also made the distinction between talking with choir members and talking with people who had not been affected by cancer ^[h]. Participants offered various examples of how the choirs offer support for people with cancer. These include knowledge of shared experiences, offering support and advice, sending cards when choir members are unwell, visiting choir members in hospital, and celebrating successful treatment ^[i]. Although the choirs provide a supportive environment, participants repeatedly stressed that cancer is not an inevitable topic of conversation. Because of this, some participants veered away from the notion of the choirs as a 'support group' ^[j].

Seventeen interview participants stated that choir singing formed a positive distraction from cancer and other chronic health problems such as depression and musculoskeletal problems ^[k, l]. Three participants who had lost someone through cancer also spoke about how choir singing distracted them from the pain of bereavement. Ten participants specifically relayed how choir singing had helped them, a family member or friend cope with the symptoms of cancer and the side effects of treatment ^[m, n]. Whilst this support was related to choir singing generally (both music and social contact), two participants specifically reflected on how singing provides a supportive environment ^[o]. Seven participants also spoke about the choirs

offering self-worth and purpose to people affected by cancer, in this way creating an alternative identity to that of patient (or carer, bereaved family member, and so on) [p]. Related to this was the notion of living life to the full regardless of cancer [q].

Reasons given for leaving the choirs by six former choir members were varied: two participants found it difficult to attend rehearsals due to lack of transport; one participant reported a lack of self-motivation in general; one participant was too busy to attend; one participant disliked the genre of music; one participant disliked the rehearsal style; and one participant felt that she was too ill to attend.

Discussion

This is the first large study to investigate choir singing as a novel support mechanism for patients and non-patients affected by cancer, using a mixed methodological approach. On joining the choir there was a significant difference in HRQoL between patients and non-patients. Patients with cancer had an overall mental health score 7 points lower, an overall physical health score 8 points lower, and a depression score 1 point greater than non-patients, whilst HRQoL scores for non-patients were comparable to normative data from the Welsh Health survey (Burholt and Nash 2011). After 6 months of attending the choir there was an improvement in patients' vitality, overall mental health and anxiety; whilst non-patients demonstrated lower anxiety scores with choral singing. In patients, the median change in overall mental health was 9 which may be considered to be clinically relevant as it exceeded the minimum clinically important difference (MCID) seen in other chronic health conditions such as Crohns disease, where MCID for overall mental health ranged from 2.3 to 8.7 points (Coteur et al, 2009), and the 2.5 MCID reported in other conditions (Strand et al, 2012). There appeared to be a gradual improvement in vitality and mental health from baseline to 3 months and further gains up to 6 months, this may suggest that the longer duration of membership the greater the benefit, although the clinical relevance of these differences require further investigation. From the qualitative analysis, participants experienced the choirs as both an uplifting musical activity and a supportive community group. It seems that the two together contributed to perceived improvements in HRQoL.

Reasons for impaired HRQoL and increased depression in patients with cancer may be due to ongoing physical, psychological and emotional problems as suggested by the National Cancer Survivorship Survey (Elliott et al, 2011). However the qualitative results suggest that cancer may be as emotionally demanding for family members and carers as for patients. A large proportion of participants were non-patients reflecting the far-reaching impact of cancer

also substantiated by the findings from other studies (Coulson and Greenwood 2012, Hudson et al, 2002, Lorenz 1998, Ream et al, 2013). Participants were largely female in-keeping with data from a large cross-sectional study of choir singing from UK, Germany and Australia (Clift et al, 2010) and a UK survey of cancer support group membership (Stevinson et al, 2011). Consistent with the general population female non-patients, but not cancer patients, had lower SF36 scores than males (Bowling et al, 1999), possibly as healthy women report health symptoms more often than males (Robert H. Wood et al, 2005).

Our results can be compared to only one similar but smaller study demonstrating increased HRQoL for people affected by cancer engaged in choir singing (Gale et al, 2010). Likewise, in a systematic review, the benefits of music therapy on HRQoL, mood and anxiety in cancer patients has been demonstrated (Bradt et al, 2011). In healthy populations several studies have illustrated the benefits of choir singing including improved mood, enhanced QoL, greater happiness, emotional wellbeing and reduced stress (Clift et al, 2010) and studies in a variety of clinical populations including chronic lung disease, have demonstrated mixed results (Morrison et al, 2013) compared to other group support interventions (Solé et al, 2010). Nevertheless, it appears that choirs can provide group support compared to no intervention (Lord et al, 2010), and this may be a useful support mechanism for both patients and non-patients affected by cancer. Our results indicate that participants experienced singing as an uplifting and communal activity which helped them to cope with cancer, cancer treatments, and loss through cancer. The role of choir communities in increasing opportunities for social interaction and support, and engendering a sense of belonging was a major theme reflecting the findings of other studies on choir singing (Bailey and Davidson 2005, Baines and Danko 2010, Bannan and Montgomery-Smith 2008, Dingle et al, 2012, Southcott and Joseph 2013).

Attrition was an unforeseen issue in our study with only 27% completion overall (although attendance was high in those who completed the assessments). This is similar to a previous, smaller longitudinal study of choir singing in which only 30% of participants completed follow-up questionnaires and demonstrated improvements in wellbeing, problems and functioning as part of The CORE Outcome Measure (CORE-OM) (Clift and Morrison 2011). As substantiated by the qualitative data, many instances of absence resulted from poor health; indeed in our study patients who did not complete all study assessments had lower HRQoL and greater anxiety and depression. However attrition was also likely a result of participants not wanting to continue with the choir. Data on dropout rates of amateur choirs are sparse and anecdotal and it is unclear whether retention is a widespread issue; however there is some data available on cancer support group membership. A UK survey of cancer

patients indicates that the mean length of support group membership is 56 months, with 80.9% of members attending more than three quarters of the time (both figures higher than in our study) (Stevinson et al, 2011). Despite these figures, initial uptake of traditional support groups is low. For example in a study of cancer survivors only 7.6% of eligible participants chose to join a self-help support group (Sautier et al, 2014). Similarly, in a study of 217 patients with a diagnosis of cancer, 67% of women and 87% of men failed to join a support group (Krizek et al, 1999). A further study identified reasons why uptake of traditional support groups may be low including the perception that support groups are negative places, pre-existence of alternative support, and perceptions around support groups and personality types (Ussher et al, 2006). Data from our own study showed that the majority of interview participants had never joined a traditional support group, with support derived mainly from other family members. One possibility is that these people would not have engaged in a traditional support group anyway thus limiting the comparisons which can be made between traditional support groups and choirs.

Although the changes associated with choir participation in this research mimic the benefits of traditional cancer support groups (including reduced levels of anxiety and depression, increased feelings of belonging to a community, increased sense of hope and control, and increased overall quality of life (Ashing-Giwa et al, 2012, Ussher et al, 2006, Zabalequi et al, 2005)) there is also evidence that support needs to be individualised and that one type might not suit all. For example, in a study of cancer support group leavers (Ussher et al, 2006) 36% stated 'it's time to move on' as a reason for leaving a traditional support group after 6 months; similarly others felt that it was time to move away from their cancer identity which they felt the support group reaffirmed. Conversely, qualitative data from our own study suggests that the choirs facilitate 'moving on' through engagement in expanding social networks, concerts, learning new repertoire and increasing musical skills; participants also stated that the choirs do not affirm cancer identity but offer an alternative, positive identity as that of a choir member. Again this suggests that straight comparisons between traditional support groups and choirs may be limited and that the choirs add to a portfolio of support options.

We acknowledge a number of limitations to our study. First, the rate of attrition was high and, as the choirs were set up as a support service, we did not recruit a control group for comparison. This high rate of attrition should be a consideration in the design of future choir-support studies including comparative studies. It also warrants further investigation in terms of identifying what motivates a person to continue/discontinue with choir singing and whether different types of support (choir singing, traditional support groups, support centred

around other activities) can be matched with personality types. We also recognise that there may be differences in health status between the subgroups of our sample (i.e. current patients, cancer survivors, carers, family members, friends and individuals who have been bereaved) and this will be explored in future analysis. Recruitment of former choir members for participation in qualitative interviews was particularly difficult, thus reasons why some people choose to leave the choir requires further investigation. The study also did not explore long term effects of choir participation beyond six months.

Conclusion

This study suggests that choirs may provide support for patients with past or current cancer and people affected by cancer such as carers, relatives and friends, as an additional or alternative approach to traditional support groups and the support provided by healthcare professionals. The results suggest that choirs can be a life-enhancing experience for those who wish to engage in them, including those who may not access traditional support groups. Specifically, over time, choir singing may improve the overall mental health, vitality and anxiety of cancer patients and enable others affected by cancer to cope with its far-reaching effect. Perceptions of improved mood, positive distraction, ability to cope, increased self-worth, purpose and identity, and possible physical benefits appear to result from the combined creative and social experience of choir singing as opposed to singing or social interaction in isolation; however this requires further investigation as does the very real issue of dropout. Choirs are an intervention which alongside other organised activities and traditional support groups may provide a spectrum of support necessary to address the different needs and preferences of those affected by cancer.

Conflict of interest

The authors have full control over primary data and allow the journal to review this if requested. Two of the authors [IL, RD] are employed by Tenovus Cancer Care which part funded this study and delivers Sing With Us, however both authors were blinded to the study analysis.

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References

- Ashing-Giwa, K., Tapp, C., Rosales, M., McDowell, K., Martin, V., Santifer, R. H., Clark, P., Steward, J., Lewis, L. and Mitchell, E. (2012) Peer-based models of supportive care: the impact of peer support groups in African American breast cancer survivors. *Oncology Nursing Forum*, 39(6), 585-591.
- Bailey, B. A. and Davidson, J. W. (2005) Effects of group singing and performance for marginalized and middle-class singers. *Psychology of Music*, 33, 269-303.
- Baines, S. and Danko, G. (2010) Community mental health music therapy: A consumer-initiated song-based paradigm. *Canadian Journal of Music Therapy*, 16(1), 148-191.
- Bannan, N. and Montgomery-Smith, C. (2008) 'Singing for the Brain': reflections on the human capacity for music arising from a pilot study of group singing with Alzheimer's patients. *The Journal of the Royal Society for the Promotion of Health*, 128(2), 73-78.
- Bannan, N. and Montgomery-Smith, C. (2008) 'Singing for the Brain': reflections on the human capacity for music arising from a pilot study of group singing with Alzheimer's patients. *The Journal of the Royal Society for the Promotion of Health*, 128(2), 73-78.
- Bonilha, A. G., Onofre, F., Vieira, M. L., Prado, M. Y. A. and Martinez, J. A. B. (2009) Effects of singing classes on pulmonary function and quality of life of COPD patients. *International Journal of Chronic Obstructive Pulmonary Disease*, 4, 1-8.
- Bowling, A., Bond, M., Jenkinson, C. and Lamping, D. (1999) Short Form 36 (SF-36) Health Survey questionnaire: which normative data should be used? Comparisons between the norms provided by the Omnibus Survey in Britain, the Health Survey for England and the Oxford Healthy Life Survey. *Journal of Public Health*, 21(3), 255-270.
- Bradt, J., Dileo, C., Grocke, D. and L, M. (2011) Music interventions for improving psychological and physical outcomes in cancer patients. *Cochrane Database of Systematic Reviews*, 8.
- Bui, L. L., Last, L., Bradley, H., Law, C. H., Maier, B. A. and Smith, A. J. (2002) Interest and participation in support group programs among patients with colorectal cancer. *Cancer Nursing*, 25(2), 150-7.
- Burholt, V. and Nash, P. (2011) Short Form 36 (SF-36) Health Survey Questionnaire: normative data for Wales. *Journal of Public Health*, 33(4), 587-603.
- Camic, P. M., Williams, C. M. and Meeten, F. (2011) Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*.

- Clift, S., Hancox, G., Morrison, I., Hess, B., Kreutz, G. and Stewart, D. (2010) Choral singing and psychological wellbeing: Quantitative and qualitative findings from English choirs in a cross-national survey. *Journal of Applied Arts and Health*, 1(1), 19-34.
- Clift, S. and Morrison, I. (2011) Group singing fosters mental health and wellbeing: findings from the East Kent "singing for health" network project. *Mental Health & Social Inclusion*, 15(2), 88-97.
- Clift, S., Nicol, J., Raisbeck, M., Whitmore, C. and Morrison, I. (2010) Group singing, wellbeing and health: a systematic mapping of research evidence. *UNESCO Observatory*, 2(1), 1835-2776.
- Coteur, G., Feagan, B., Keininger, D. and Kosinski, M. (2009) Evaluation of the meaningfulness of health-related quality of life improvements as assessed by the SF-36 and the EQ-5D VAS in patients with active Crohn's disease. *Alimentary pharmacology & therapeutics*, 29(9), 1032-1041.
- Coulson, N. S. and Greenwood, N. (2012) Families affected by childhood cancer: an analysis of the provision of social support within online support groups. *Child: Care, health and development*, 38(6), 870-877.
- Creswell, J. W. (2009) *Research Design. Qualitative, quantitative and mixed methods*, London: Sage.
- Dingle, G. A., Brander, C., Ballantyne, J. and Baker, F. A. (2012) 'To be heard': The social and mental health benefits of choir singing for disadvantaged adults. *Psychology of Music*.
- Elliott, J., Fallows, A., Staetsky, L., Smith, P. W. F., Foster, C. L., Maher, E. J. and Corner, J. (2011) The health and well-being of cancer survivors in the UK: findings from a population-based survey. *Br J Cancer*, 105(S1), S11-S20.
- Gale, N., Enright, S., Reagon, C., Lewis, I. and van Deursen, R. (2010) A pilot investigation of quality of life and lung function following choral singing in cancer survivors and their carers. *Ecancermedicalscience*, 6(261).
- Gottlieb, B. H. and Wachala, E. D. (2007) Cancer support groups: a critical review of empirical studies. *Psycho-oncology*, 16, 379-400.
- Hoey, L. M., Leropoli, S. C., White, V. M. and Jefford, M. (2008) Systematic review of peer-support programs for people with cancer. *Patient Education and Counselling*, 70(3), 315-37.
- Hudson, P. L., Aranda, S. and McMurray, N. (2002) Intervention development for enhanced lay palliative caregiver support - the use of focus groups. *European Journal of Cancer Care*, 11(4), 262-70.

- Kenny, D. T. and Faunce, G. (2004) The impact of group singing on mood, coping and perceived pain in chronic pain patients attending a multidisciplinary pain clinic. *Journal of Music Therapy*, 3, 241-258.
- Krizek, C., Roberts, C., Ragan, C., Ferrara, J. and Lord, B. (1999) Gender and cancer support group participation. *Cancer practice*, 7(2), 86-92.
- Lesta, B. and Petocz, P. Familiar Group Singing: Addressing mood and social behaviour of residents with dementia displaying sundowning. *Austrian Journal of Music Therapy*, 17, 2-17.
- Lord, V., Cave, P., Hume, V., Flude, E., Evans, A., Kelly, J., Polkey, M. and Hopkinson, N. (2010) Singing teaching as a therapy for chronic respiratory disease - a randomised controlled trial and qualitative evaluation. *BMC Pulmonary Medicine* 2010, 10:41, 10(41).
- Lord, V., Hume, V., Kelly, J., Cave, P., Silver, J. and Waldman, M. (2012) Singing classes for chronic obstructive pulmonary disease: a randomized controlled trial. *BMC Pulmonary Medicine*, 12(69).
- Lorenz, L. (1998) Selecting and implenting support groups for bereaved adults. *Cancer Practice*, 6(3), 161-6.
- Macmillan Cancer Support (2013) *Cancer Mortality Trends 1992-2020: Macmillan Cancer Support*.
- Middleton, R. J. (2014) Meeting the psychological care needs of patients with cancer. *Art and Science*, 28(21), 39-45.
- Morrison, I., Clift, S., Page, S., Salisbury, I., Shipton, M., Skingley, A. and Burrows, T. (2013) A UK feasibility study on the value of singing for people with Chronic Obstructive Pulmonary Disease (COPD). *UNESCO Observatory Multi-Disciplinary Journal in the Arts*, 3(3), 1-19.
- Pascoe, S., Edeman, S. and Kidman, A. (2000) Prevalence of psychological distress and use of support services by cancer patients at Sydney hospitals. *Australian New Zealand Journal Psychiatry*, 34(5), 785-91.
- Ream, E., Pedersen, V. H., Oakley, C., Richardson, A., Taylor, C. and Verity, R. (2013) Informal carers' experiences and needs when supporting patients through chemotherapy: a mixed method study. *European Journal of Cancer Care*, 22(6), 797-806.
- Robert H. Wood, P. H. D., Rebecca Ellis Gardner, P. H. D., Kellye A. Ferachi, M. S., Christina King, M. S., Andrea Ermolao, M. D., Katie E. Cherry, P. H. D., M Elaine Cress, P. H. D. and S Michal Jazwinski, P. H. D. f. t. L. H. A. S. (2005) Physical Function and Quality of Life in Older Adults: Sex Differences. *Southern Medical Journal*, 98(5), 504-512.

- Sautier, L., Mehnert, A., Hocker, A. and Schilling, G. (2014) Participation in patient support groups among cancer survivors: do psychosocial and medical factors have an impact? *European Journal of Cancer Care*, 23, 140-148.
- Solé, C., Mercadal-Brotons, M., Gallego, S. and Riera, M. (2010) Contributions of Music to Aging Adults' Quality of Life. *Journal of Music Therapy*, 47(3), 264-281.
- Southcott, J. and Joseph, D. (2013) Community, commitment and the then 'Commandments': Singing in the Coro Furlan, Melbourne, Australia. *International Journal of Community Music*, 6(1), 5-21.
- Stephen, J., Collie, K., McLeod, D., Rojubbally, A., Fergus, K., Speca, M., Turner, J., Taylor-Brown, J., Sellick, S., Burrus, K. and Elamly, M. (2014) Talking with text: communication in therapist-led, live chat cancer support groups. *Social Science and Medicine*, 104(178-86).
- Stevinson, C., Lydon, A. and Amir, Z. (2011) Cancer support group participation in the United Kingdom: a national survey. *Support Care Cancer*, 19, 675-683.
- Strand, V., Sharp, V., Koenig, A. S., Park, G., Shi, Y., Wang, B., Zack, D. J. and Fiorentino, D. (2012) Comparison of health-related quality of life in rheumatoid arthritis, psoriatic arthritis and psoriasis and effects of etanercept treatment. *Annals of the Rheumatic Diseases*, 71(7), 1143-1150.
- Tamplin J, Baker FA and Jones B, e. a. (2013) 'Stroke a Chord': the effect of singing in a community choir on mood and social engagement for people living with aphasia following a stroke. *Neurorehabilitation*, 32, 929-941.
- Ussher, J., Kirsten, L., Butow, P. and Sandoval, M. (2006) What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science and Medicine*, 62(10), 2565-76.
- Ware Jr, J. E. and Gandek, B. (1998) Overview of the SF-36 Health Survey and the International Quality of Life Assessment (IQOLA) Project. *Journal of Clinical Epidemiology*, 51(11), 903-912.
- Zabalequi, A., Sanchez, S., Sanchez, P. D. and Juando, C. (2005) Nursing and cancer support groups. *Journal of Advanced Nursing*, 51(4), 369-81.
- Zigmond, A. S. and Snaith, R. P. (1983) The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand*, 67, 361-370.

Table 1: Sing with Us choir locations*, start date and number of study participants per location.

Choir	Start Date	Study Participants n=	Study Participants %	Study Patient n=	Study Non-patients n=	Patient %
Aberystwyth	28 April 2014	42	5%	8	34	19%
Abergavenny	26 March 2013	88	11%	14	74	16%
Bangor	19 September 2013	72	9%	18	54	25%
Barry	3 September 2013	46	6%	11	35	24%
Bridgend	8 April 2013	46	6%	18	28	39%
Carmarthen	27 September 2012	29	4%	9	20	31%
Cardiff	7 March 2012	145	18%	50	95	34%
Cwmbran	30 April 2012	70	9%	25	45	36%
Llandudno	15 April 2014	51	6%	12	39	24%
Llanelli	21 January 2014	25	3%	6	19	24%
Merthyr	29 October 2013	43	5%	8	35	19%
Swansea	17 April 2012	71	9%	17	53	25%
Wrexham	1 July 2013	88	11%	26	62	30%
Total		816		222	593	27%

*2 choirs excluded due to small numbers of questionnaires completed at the time of analysis

Table 2: Initial health status in patients and non-patients;

	Patient n=222	Non-patient n=593	p-value
Sex male:female	33:189	92:501	0.817
Age (yrs)	62 (21-84)	56 (18-88)	<0.001**
Rehearsals Attended	16 (4-43)	14 (5-32)	0.655
Choir Membership (wks)	28 (7-65)	25 (8-49)	0.234
Attendance %	70 (49-84)	70 (54-83)	0.345
Physical Functioning	84 (55-95)	90 (80-100)	<0.001**
Physical Role	75 (38-94)	94 (75-100)	<0.001**
Bodily Pain	68 (45-90)	80 (68-100)	<0.001**
General Health	60 (45-80)	70 (55-85)	<0.001**
Vitality	50 (31-63)	56 (44-75)	<0.001**
Social Functioning	75 (50-100)	88 (63-100)	<0.001**
Emotional Role	75 (50-100)	92 (75-100)	<0.001**
Mental Health	70 (55-80)	70 (55-85)	0.058
Overall Physical Health	71 (48-85)	<u>78 (65-89)</u>	<u><0.001**</u>
Overall Mental Health	69 (51-81)	76 (60-87)	<0.001**
Anxiety	7 (4-10)	7 (4-10)	0.171
Depression	4 (1-7)	3 (1-6)	0.003**

Data are median (interquartile range):** p<0.01= Highly statistically significant

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Table 3: Health-related quality of life, anxiety and depression (SF36 and HAD scale) in comparing patients and non-patients at the initial assessment and scores at 3 and 6 month assessment.

Patient	Non-complete n=162	Initial n=60	3 months	6 months	Initial, 3 6 month p
Male: female (n)	25:137	8:52	-	-	-
Age (years)	62 (53-68)	62 (55-66)	-	-	-
Rehearsal Attendance (%)	67 (44-86)**	75 (67-84)	-	-	-
Choir Choir Durationmembership (weeks)	15 (4-48)**	61 (37-79)	-	-	-
Vitality	50 (31-63)*	53 (44-67)	59 (50-75)	63(50 -75)	0.007**
Overall Physical Health	67 (45-82)**	79 (65-92)	80 (61-90)	80 (64-90)	0.107
Overall Mental Health	66 (48-80)**	73 (58-86)	81 (68-89)	82 (62-89)	0.005**
Anxiety	8 (5-10)*	6 (3-9)	6 (3-8)	6 (3-7)	0.008**
Depression	4 (2-7)**	3 (1-5)	2 (1-5)	2 (1-4)	0.071
Non-patient	Non-complete n=450	Initial n=143	3 months	6 months	Initial, 3 6 month p
Male: female	71:379	21:122	-	-	-
Age (years)	55 (43-64)	55 (44-64)	-	-	-
Rehearsal Attendance (%)	67 (50-84)**	74 (67-74)	-	-	-
Choir Duration membership (weeks)	16 (6-39)**	42 (32-67)	-	-	-
Vitality	56 (42-75)*	63 (50-75)	63 (50-75)	63(50 -75)	0.619
Overall Physical Health	86 (69-94)	84 (71-94)	84 (69-93)	83 (65- 93)	0.862
Overall Mental Health	77 (58-86)	78 (64-89)	78 (69-89)	82 (68-90)	0.335
Anxiety	7 (4-10)*	6 (3-9)	6 (3-8)	5 (2-8)	0.018*
Depression	3 (1-7)*	2 (1-4)	2 (1-5)	2 (1-5)	0.524

Data are median (IQR) *p<0.05, ** p<0.01; Statistical significance difference between initial assessment of individuals who completed all questionnaires and those who did not (non-complete).

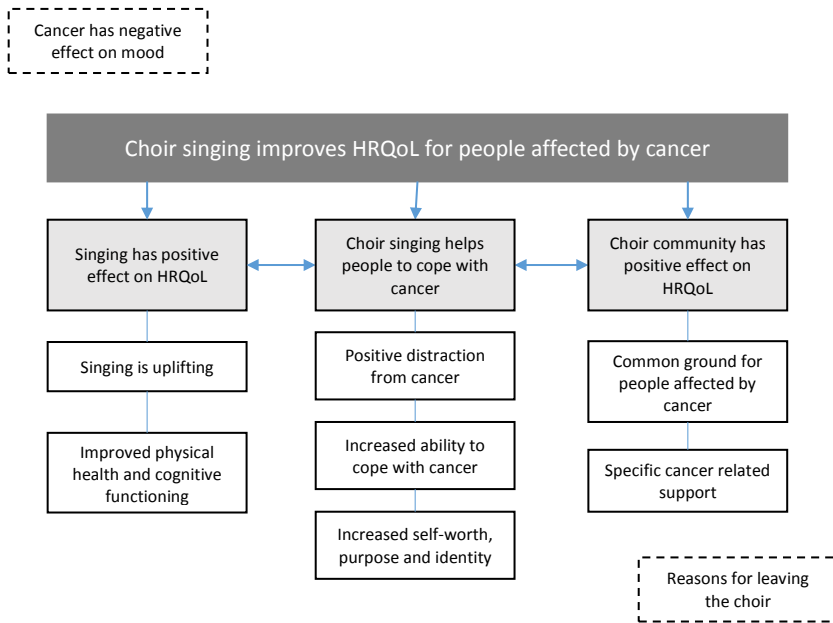
Table 4: Participant quotes by theme.

Theme	Ref	Data (participant)
Cancer has negative effect on mood	[a]	<i>I think I had to be strong for everyone else in the family if you know what I mean? My mum and my one sister they didn't cope at all, so I didn't show any emotion, I was happy throughout even though I didn't feel it at times. (Male, cancer patient)</i>
	[b]	<i>It's a waiting game then, there's no definitive answer given to you, no 'yes you're all clear' or 'yes you're all fine', nothing like that, you have to sit back and wait. (Male, cancer survivor)</i>

Singing is uplifting	[c]	<i>The feel good factor. [Singing] must do something to your blood, to your endorphins or something, because it gives you a happy buzz. Like a chocolate fix. (Female, bereaved family member)</i>
	[d]	<i>I enjoy the singing immensely, I like the songs that we chose, they're always uplifting and they're well worked out harmonies. (Female, bereaved family member)</i>
	[e]	<i>If I'm feeling a bit down and I go along, then I feel much better and it takes me through the rest of the week then. It's quite nice. Yes, it definitely makes me feel better. I sing in the car on the way to work as well. (Female, bereaved family member)</i>
Common ground for people affected by cancer	[f]	<i>You feel very at ease with people because they know what you've been through. (Male, cancer patient)</i>
	[g]	<i>Even though I don't know the names of everyone, I do feel that we are very close and like a little family ...I think it's because of the experiences that we share and the fact that we have been touched by cancer. (Female, cancer survivor)</i>
	[h]	<i>I think it's good to [talk to] people who have been through something similar... about things that you don't want to talk to your husband or your boyfriend about, [because] you don't want to worry them ... People who have not been through that trauma don't really understand. (Female, cancer survivor)</i>
Specific cancer related support	[i]	<i>You might see that someone's upset, you don't know why but you go and give them a hug. (Female, bereaved family member)</i>
	[j]	<i>We do get support from each other but only when we need it, we don't talk about cancer all the time. (Female, cancer patient)</i>
Positive distraction from cancer	[k]	<i>The choir has given me a focus rather than sitting back and just feeling awful and feeling sad about things (Male, cancer patient)</i>
	[l]	<i>For an hour and a half everything else just goes out of the door, you get completely away from every concern. I have had a few issues over hospitals and treatment and it just takes it away for the hour and a half completely. (Male, cancer patient)</i>
Increased ability to cope with cancer	[m]	<i>It's a step above the pain and perhaps blocks off the negative thoughts. (Bereaved family member)</i>
	[n]	<i>I was so anxious because I had to go back to the hospital every month and I think that was a worry in itself. I was feeling a bit depressed because I was thinking, oh the cancers coming back and I was thinking, oh how am I going to cope and everything. So it helped with the positivity that I had lost. (Female, cancer survivor)</i>
	[o]	<i>When you sing in harmony it's a way of supporting each other when you sing like that. You really need to listen to your cues, where your entry is, so it's mirroring life in your choir, being mutually supportive and listening to each other. (Female, bereaved family member)</i>
Improved self-worth, purpose and identity	[p]	<i>When I come into that hall, I don't think I'm someone who's got cancer. We come in here and I just think I've come to meet all my friends tonight (Focus group participant)</i>
Choir singing helps people to cope with cancer	[q]	<i>I think that a lot of people think that when people have cancer, that's the end of it. But this shows that it's not actually the end of it and you will get over it, whether they actually do or they don't is irrelevant, it seems irrelevant. It's oh I've got this but sod it I'm going to enjoy myself regardless, I think that really is what shines through more than anything. (Female, cancer patient)</i>

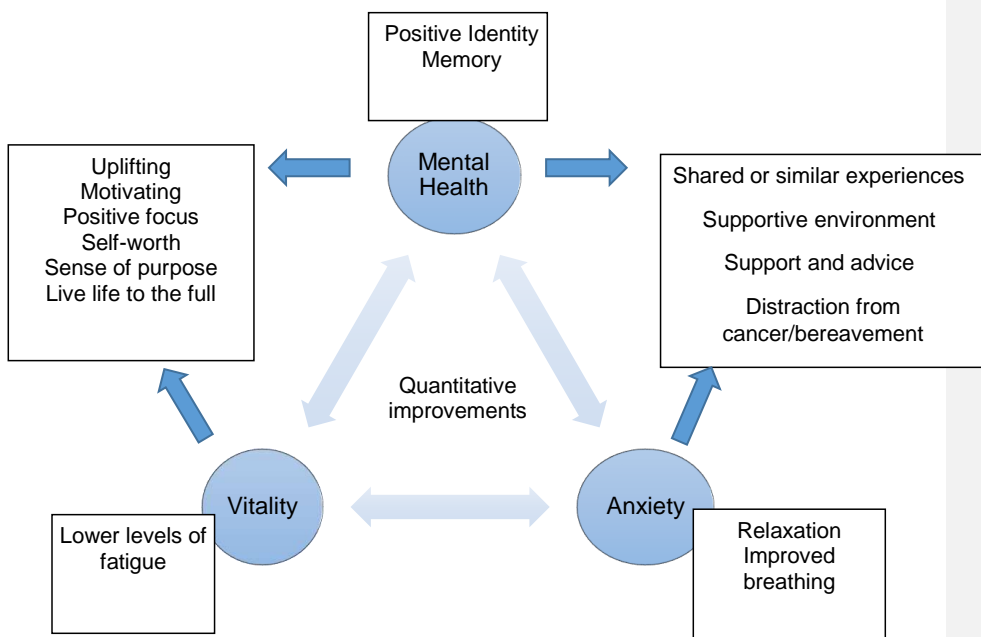
*Ref indicates the reference code used to report the qualitative data in the main text

Fig. 1 Themes derived from the qualitative data



Broken lines indicate standalone themes. Strength of theme determined by number of quotes is indicated by darkness of box (the darkest box being the overarching theme). Arrows indicate interrelation of themes.

Fig. 2 Benefits of choir singing – areas of convergence between quantitative and qualitative data



Circles represent quantitative benefits of choir singing, boxes represent related qualitative benefits.