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# **Evaluation of 'Dancing for Health' partner dancing programme for people affected by incurable illness**

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An evaluation by Dr Jenni Brooks of Sheffield Hallam University, and Janet Morrison and Dr Peter Goodwin of Manchester Metropolitan University.

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## Summary

- This report is an evaluation of a 'Dancing for Health' partner dancing programme run at Clifford House in Sheffield in 2017-2018. The evaluation used both quantitative and qualitative methods to assess the impact of the programme on physical and mental wellbeing and relationships.
- The quantitative work showed that eight weeks of Dancing for Health leads to a reduction in perceived stress for those with an illness with no cure, partners, or the bereaved; and for partners, there was an improvement in social functioning. However the data showed little improvement in terms of quality of life, and there was a mixed picture in terms of health status.
- The qualitative work demonstrated that dancers understood the importance of exercise, and were engaged in many other forms of physical activity, not just the dancing programme. All dancers, including those without incurable illnesses themselves, appreciated the adaptations made to the dance steps, and many were more likely to attend Dancing for Health than their other exercise classes. Dancers valued the opportunity to socialise, both within the class and in some cases outside - this was particularly important for those living alone.
- Overall, this study shows that the Dancing for Health programme, specifically tailored for people with health conditions, can be a positive and enjoyable way to increase both exercise and social connections for people with incurable illness, partners, and bereaved people.

## 1. Introduction

In September 2017, St Luke's Hospice in Sheffield opened Clifford House to cater for people who have been diagnosed with an illness which has no cure, but who are not in need of the more intensive care provided at the St Luke's hospice site. Clifford House is open three days each week and provides free support and activities for anyone affected by incurable illness, including that of a friend or relative.

One of the activities provided at Clifford House is Dancing for Health, a partner dancing programme created by a local dance teacher, Tracey Barnes of Smartdanceworks, to cater specifically for people with health conditions, and designed to accommodate limited movement, need for rest and other requirements.

In 2018, Dancing for Health asked researchers at Manchester Metropolitan University and Sheffield Hallam University to evaluate the Dancing for Health programme at Clifford House. The aims were to evaluate the Dancing for Health programme in terms of physical wellbeing, mental wellbeing and the effect on relationships.

## 2. Background

Research demonstrates the positive physical benefits of dancing (Hwang and Braun, 2015), and there is evidence that partner dancing is associated with perceived improvements in physical fitness and mental wellbeing (Lakes et al, 2016). Therapeutic use of dance can have a positive effect on health-related psychological outcomes such as quality of life, clinical outcomes (particularly anxiety and depression), well-being, mood and body image (Koch et al, 2013). Dancing can reduce cancer-related fatigue (Sturm et al, 2014), and there is some evidence that dance or movement therapy may have a beneficial effect on quality of life for cancer patients, but the overall quality of evidence is low (Bradt et al, 2015).

The evidence base for the effects of dancing on people with incurable illness is limited, although palliative care patients have reported improvements in breathing and mobility, as well as enjoyment, relaxation and social benefits of attending dance and yoga classes (Selman, Williams and Simms, 2012). As well as deterioration in their physical health over time, people with incurable illnesses may experience stress and decline in mental wellbeing (Lehto et al, 2018). Their partners, family members and friends may also feel grief, anxiety about the future, and potentially stress associated with a new caring role (Nielsen et al, 2016). Coping with terminal illness can feel isolating, and may lead to changes in relationships (Martín, Olano-Lizarraga, and Saracíbar-Razquin (2016).

As the UK population ages, more people are living with complex needs as a result of terminal illness. Hospices can provide support at the end of life, but there is little specific support for people who have been recently diagnosed and may have some considerable time to live with their incurable illness before they reach the end of their life (Beernaert et al, 2016). Finding ways for them to live well, supporting movement in a gentle environment, and fostering supportive relationships both for people living with incurable illness themselves and those who are supporting others is an important contribution.

### **3. Aims of the evaluation**

The aims of this evaluation were to assess the Dancing for Health programme run at Clifford House for people affected by incurable illness. We explored the effects of the programme on

- Physical wellbeing
- Mental wellbeing
- Relationships

### **4. Dancing for Health sessions**

Dancing for Health sessions began in September 2017 and took place on Wednesday afternoons. Dancers booked onto the sessions through the main Clifford House online booking system for six weeks at a time, although many repeatedly extended their bookings.

Each session lasted for two hours, and began with an introduction to the steps that would be learned that week. The instructor, Tracey, demonstrated the steps with one of her assistants, and then dancers were encouraged to find a partner.

Once in pairs, the dancers lined up down the room, with one line being designated as 'leaders' and the other as 'followers'. Tracey taught each step in turn, repeating each without music until most people had mastered it, then repeating again several times with music. After each repeat, the followers would move down the room to dance with the next leader. Partners would introduce themselves, then practice again before moving on.

After about an hour, there was a break. Dancers either stayed in the room (some practicing, some chatting, some resting), or moved to the large shared kitchen where there was free tea and coffee, and often cakes.

After the break, Tracey recapped the routine so far, and then taught the remaining steps until everyone had learned the whole routine. At around 3.50pm, the class finished but the music stayed on, and people could stay to practice.

## 5. Methods

We used three methods to evaluate the Dancing for Health programme.

- Quantitative evaluation of physical and mental wellbeing (led by Janet Morrison and Peter Goodwin, Manchester Metropolitan University), involving:
  - 36-item Short Form Health Survey (SF-36) developed by RAND as part of the Medical Outcomes Study
  - Functional Assessment of Cancer Therapy scale (FACT-G) (Cella et al, 1993)
  - Perceived Stress Scale (Cohen, Kamarck and Mermelstein, 1994)
- Qualitative observation of dancing sessions (led by Jenni Brooks, Sheffield Hallam University)
- Qualitative interviews with dancers affected by incurable illness, whether their own or that of a relative or friend (led by Jenni Brooks)

Jenni and Janet attended several sessions at the start to introduce the study and invite people to participate. Participant information sheets and consent forms were given out and either completed before the end of the class or taken home and returned the following week. Given the shortage of leaders, we both joined in with the dancing on occasions which allowed us to get to know people, allowed the dancers to get to know us. Ethical approval was obtained from Manchester Metropolitan University ref: 1506.

### 5.1 Quantitative evaluation of physical and mental wellbeing

The self-administered questionnaires were completed by each participant at their first visit and then approximately every 8-weeks for 40-weeks or for as long as they attended the classes. The participants completed the questionnaires at the end of the class or were able to take the questionnaires home to fill in at their convenience.

#### *SF-36 Questionnaire*

The SF-36 questionnaire is a generic measure of health status, consisting of 36 questions grouped into eight health-related aspects of a person's life. The domains include; physical functioning, role limitations due to physical health, role limitations due to emotional, energy/fatigue, emotional well-being, social functioning, pain and general health. It was used within this study to provide a population-based measure of health status including physical and mental health domains. Its usefulness within a population who are diagnosed with life-limiting conditions has been demonstrated. Scores measured between 0 and 100 for each of the eight domains. A higher score represents better health.

### *Perceived Stress Scale-10 Questionnaire*

The PSS-10 measures the degree to which situations in a person's life are considered stressful. The overall score measures between 0 and 40. A lower score represents less stress.

### *FACT-G Questionnaire*

The FACT-G questionnaire is a 28-item general cancer quality of life measure for evaluating patients receiving cancer treatment within four domains; physical, social/family, emotional and functional. It is a valid and reliable instrument to measure quality of life within this population. Scores measured between 0 and 28 for the physical, social and functional well-being domains, 0 and 24 for emotional well-being and 0 and 108 for an overall total. A higher score represents better health.

## **5.2 Qualitative observation and interviews**

Jenni attended and observed sessions approximately every eight weeks between September 2017 and August 2018. Observations focused on the format of the sessions and interactions between dancers. Fieldnotes were recorded electronically and later transcribed.

Towards the end of the Dancing for Health programme, Jenni invited thirteen people to take part in an interview about their experiences. Everyone who was invited agreed. Interviews lasted approximately 30-45 minutes, and covered:

- how people found out about the sessions
- why they decided to sign up
- physical wellbeing
- mental wellbeing
- relationships

Most people were interviewed individually, but three people who knew each other well asked to be interviewed together.

Interviews took place primarily at Clifford House at times to suit the participants. Many dancers attended morning sessions at Clifford House, or came early to take part in the shared lunch, so most of the interviews took place before the dancing sessions in a side room. Two of the interviews took place in people's own houses on their request.

Interviews were audio recorded and transcribed, managed using NVIVO software and analysed thematically. All names have been changed for confidentiality.

## 6. Findings

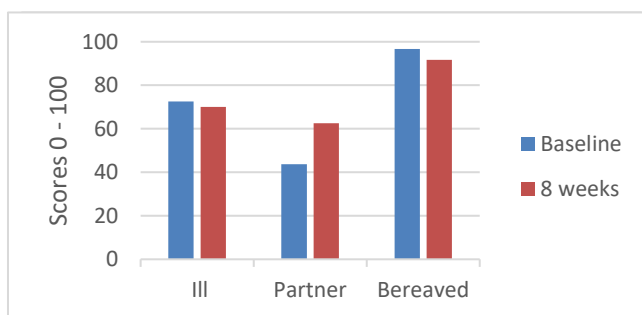
### 6.1 Quantitative evaluation of physical and mental wellbeing

22 people consented to take part in the study. Due to attrition and missing data, there was only a complete set of data for baseline and eight weeks for ten people. These were included in the final data analysis n=10 participants. Of these n=5 participants were ill, n=3 were bereaved and n=2 were partners of an ill person.

#### 6.1.1 Health status (measured using SF-36)

Over eight weeks of dance sessions there was trend towards less role limitations due to physical health, less role limitations due to emotional problems, more energy, better emotional well-being, improved social functioning and improved overall general health. However, there was also a trend towards a decline in physical functioning and increased pain (Fig. 1). Domain abbreviations for SF-36 are shown in Table 1.

We also looked at the domains for three subgroups: those with an incurable illness (ill), partners of someone with an incurable illness (partner) and bereaved. For all domains the subgroup findings reflected their combined findings, except the social functioning domain. Whereas the ill and bereaved dancers reported a decline in social functioning, the partners reported an increase (Fig. 2).



**Figure 2** Mean Social Functioning Domain scores by subgroup

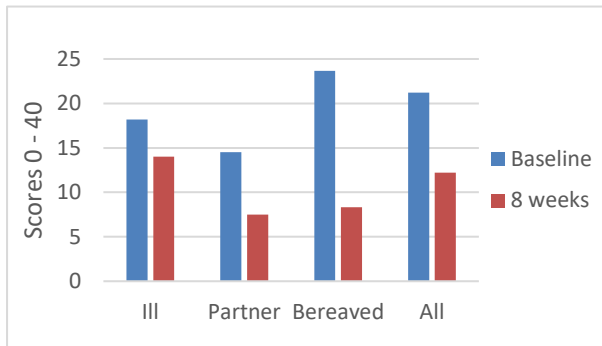
PF	Physical functioning
PH	Role limitations due to physical health
EP	Role limitations due to emotional
EF	Energy/fatigue
EW	Emotional well-being
SF	Social functioning
Pain	Pain
GH	General health

**Table 1** Key to SF-36 domain abbreviations



### 6.1.2 Perceived stress (measured using Perceived Stress Scale)

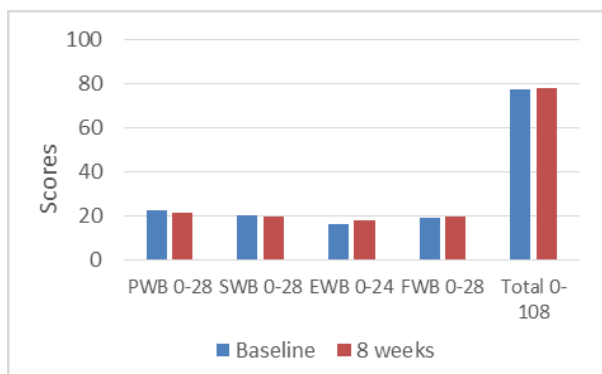
All participants considered their life to be less stressful after eight weeks of dancing (Fig. 3). The bereaved subgroup experienced the highest levels of perceived stress at the start of the eight weeks and the greatest reduction in perceived stress over the eight weeks of dancing.



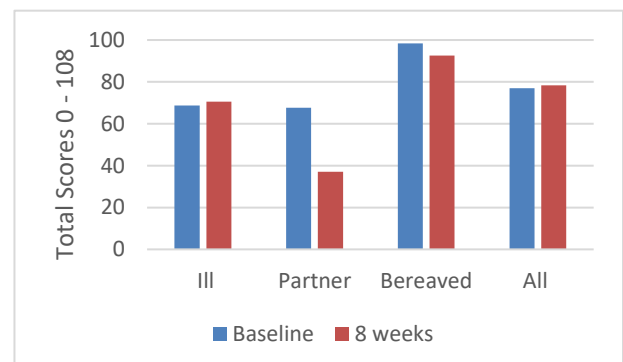
**Figure 3** Mean Subgroup and All scores for PSS

### 6.1.3 Quality of Life

There was very little change in quality of life over eight weeks of dancing. There was a slight trend towards a decrease in quality of life physically and socially and an increase in quality of life emotionally, functionally and overall (Fig. 4).



**Figure 4** Mean domain and total Fact-G scores for all participants



**Figure 5** Mean total Fact-G scores by subgroup

PWB	Physical well-being
SWB	Social well-being
EWB	Emotional well being
FWB	Functional well-being
<b>Table 2</b> Key to Fact-G domain abbreviations	

We also looked at the quality of life for total Fact G scores by subgroup which revealed that whilst the overall impression was that of an improvement in quality of life, the partners and bereaved reported a reduction in quality of life over eight weeks of dancing (Fig. 5).

## 6.2 Qualitative evaluation of physical and mental wellbeing and relationships

### 6.2.1 Why do people attend Dancing for Health?

St Luke's publicised the opening of Clifford House widely in the autumn of 2017, and most interviewees found out about Dancing for Health through the Clifford House brochure, either when attending an open day, or through the brochure being distributed by another group. One person had received an email from another group directly mentioning Dancing for Health, and a member of St Luke's staff had suggested Dancing for Health specifically to other people knowing they had an interest in dancing.

All of the interviewees had some previous experience of dancing. Some had taken part in dance lessons or shows as children; others had danced with friends in nightclubs or at organised dances. Some had taken exercise classes involving dancing (for example Zumba) or dance lessons as an adult, sometimes with their partner. Others had not danced since before their marriage. For all, Dancing for Health provided an opportunity to indulge an old interest in dancing and get some exercise in a supportive environment.

All interviewees were regular attenders, and had attended almost every week since their first session, only missing weeks due to important prior commitments or medical appointments. Many said they made a special effort to keep Wednesdays free when arranging other activities. Pseudonyms are used to protect confidentiality.

### 6.2.2 Physical wellbeing

Dancers with incurable illnesses experienced various physical symptoms due to their conditions and associated treatments, including dizziness, breathing difficulties, aching limbs, restrictions in mobility, and tiredness. The dancing sessions were designed with health needs in mind, and dancers talked about the adaptations they appreciated which allowed them to take part. For example, there was very little spinning in the routines, but the instructor explained alternatives if people did feel dizzy when turning.

Dancers always had the option to sit down if necessary, although at least one person was reluctant to do this.

*'When my legs start aching I think I'll sit down, but I don't like to do that because I don't like to give in, so when Tracey says "all change partners" and one goes out, I always choose to sit down then, so I don't look as though I'm giving in.'*

Elsie

Several bereaved dancers talked about their own health conditions, including heart failure and arthritis, and mentioned how the dancing sessions had been adapted in ways that were useful for them.

*'I've got bad arthritis in my spine and it affects my neck and shoulders, and if I'm going through a spell of that, my movement's very restricted. But the way Tracey has designed the dancing I can just about manage what they do here.'*

Gail

All dancers with incurable illness talked about the importance of physical exercise.

*'With a lot of the chemo drugs you lose balance and you lose other faculties. Now, those faculties remain longer if you are doing activities that improve them, of which dancing and the exercise class are a part too.'*

Helen

Dancers with incurable illnesses were therefore making an effort to be active in many ways, with some taking other exercise or physical rehabilitation classes, and others incorporating activity into their daily lives, for example by walking to the bus stop. It was therefore difficult for people to attribute positive physical effects specifically to the dancing sessions.

However, some people did talk specifically about how they felt dancing helped them to manage their condition.

*'I have COPD so it's a good way to exercise... it's actually helping us to remember to sit up straighter and expand our chests so it helps for the breathing.'*

Dorothy

Several people with health conditions mentioned feeling tired after dancing sessions. This was not felt to be a bad thing, rather an indication that they had done some exercise.

Bereaved people talked about having lost fitness while caring for a relative, or while grieving after their death. For them, Dancing for Health classes provided a way to regain some fitness in a relatively low-impact way, in supportive surroundings. One dancer compared Dancing for Health to another dance class she attended.

*'I don't sleep well; I tend to feel tired... I know at my other dancing class, in this heat, it's just been too much sometimes.'*

Sally

Overall, dancers, particularly those with incurable illness, were aware of the benefits of physical activity for their health, and were undertaking a variety of activities, making it difficult to associate improvements in physical fitness specifically to the Dancing for Health sessions.

However, dancers did report that Dancing for Health sessions helped with particular aspects of their physical health (for example posture), and importantly, the adaptations made to the dance steps meant people with health conditions felt comfortable participating. All dancers found the environment supportive, and reported that other people understood that some days they may feel poorly or down, but that they could still attend without having to explain themselves.

Therefore, aside from a couple of people who were attending condition-specific rehabilitation classes, most interviewees said they were more likely to come to Dancing for Health sessions than another exercise class or dance class.

### **6.2.3 Mental wellbeing**

Dancers talked about the positive effects on mental wellbeing. Many dancers discussed how Dancing for Health sessions gave them a chance to focus on something other than their situation, whether their own or someone else's illness or a bereavement.

*'I think it certainly does you good mentally because, well you're not thinking about yourself and what's the matter with you... because you're concentrating on your dancing. It takes over whilst you're here'*

Elsie

Some bereaved people had found that during a period of caring for a loved one, they had become isolated, and found it difficult to restart their previous activities. For some bereaved people in particular therefore, Dancing for Health sessions gave them a reason to get out of the house.

*'It's given me a reason for getting up and going and doing something. Otherwise, when you lose your loved one, you could just sit at home and look at that empty chair. I saw what happened to my friends, when it happened to their wives and I was determined I was not going to do that.'*

Edward

Many dancers described how they looked forward to attending Dancing for Health sessions.

*'I think my mood is lighter, it's lifted... it's not just when I'm actually here. I know that I'm coming the next week when I leave, so I'm looking forward to that. Before I started coming here, all I had in my head was visiting my husband or what was going to happen to him, which I still get but not 24/7.'*

Gail

People dressed smartly, and a small number of women bought special dancing shoes to attend the classes. One woman described how she had lost interest in clothes since she became ill, but going to Dancing for Health had reinvigorated her attention to her appearance by giving her a focus and something to dress up for.

*'I looked in the mirror, it doesn't fit me, it doesn't suit me, you know? I didn't even want to look for [new clothes] but now, coming here, with the dancing, I do... This is going out, my dancing just stimulated [thinking] about my clothes. My daughter said "what's the next thing?" I said "hairdresser!" and from there she said "are you going to have your facial?" I didn't go for about three years... but now I have my monthly facial again.'*

Grace

For some people, the increased confidence they had gained through Dancing for Health sessions had encouraged them to go on to consider dancing in other situations, for example taking another type of dancing class, or saying yes when being asked to dance while on holiday.

Dancing for Health was therefore by interviewees as having a positive effect on mental wellbeing by providing something to look forward to, an absorbing distraction during the class, and an opportunity to socialise with other people in similar situations.

#### **6.2.4 Relationships**

A small number of dancers attended Dancing for Health sessions with a spouse or friend, but the majority were alone, and all valued meeting and chatting to other people, including tutors, during the classes. This was particularly important for people who lived alone or did not meet people very often in other situations.

*'I used to get a bit "poor me" I suppose... Sometimes I get really down, but I'm getting over that now. I think just talking to people, and not only about being poorly, about all sorts of things, very rarely about being poorly.'*

Ivy

Several people mentioned the importance of the dancing to the development of new relationships. They had been involved in caring for an ill person for many years, and in the process had become isolated from circles of existing friends. When that person died or went into a nursing home, they needed new relationships, and dancing sessions had given them that.

Some of the dancers had formed new friendships and started to socialise with each other outside of the dancing sessions.

*'I come in time for lunch, so we all have a chat about all sorts of different things and exchange phone numbers. There's a group of about four or five of us who've been out for a meal.'*

Gail

Others did not see other dancers outside of the sessions, but found that the companionship within sessions was important for them. People valued others remembering their situation, even if they did not always talk about their own situations.

*'You meet them all... when you don't see them, because they all have illnesses... they'll ask you the next week, "were you ill last week?"'*

Grace

In some cases, dancers felt that attending dance sessions had improved their relationships with other family members, as it gave them something new to talk about. For example, one dancer whose husband was ill said

*'I think it improves my relationship with my husband... if you're there all the time with each other, I think it's better when you've got something you're doing differently that you can talk about.'*

Helen

The partner dancing aspect of Dancing for Health was seen as daunting at first by some people who attended sessions alone, particularly if they had only previously danced with a spouse. Others, however, valued this aspect of the sessions.

*'I guess with the partner dancing there's a connection with somebody else isn't there? It certainly releases something, some feel-good factor.'*

Sally

Overall, dancers felt like part of a group even if they were not socialising with other dancers outside of the class. They valued meeting other people in similar situations, even if they did not go on to talk about those situations much, and valued the comradeship of the sessions themselves. Some dancers had formed friendships and met up outside of the sessions. Others felt their attendance at Dancing for Health had a positive influence on their relationships with other people, for example by giving them something to talk about, or something to look forward to, and therefore improving their own mood.

## 7. Conclusions

This research gives a mixed picture of the effectiveness of the Dancing for Health programme on physical and mental wellbeing and relationships for people affected by incurable illness.

### 7.1 Conclusions from the quantitative work

An eight week Dancing for Health programme leads to a reduction in perceived stress for those with an illness with no cure, partners or the bereaved.

Compared to normative data, there was a higher than normal level of perceived stress in the ill and bereaved sub-groups and a normal level of perceived stress in the partners. After 8 weeks of dancing, the perceived stress levels for all groups were at or below normal levels.

Health status for partners improved over eight weeks of the Dancing for Health programme in terms of social functioning.

When looking at the cohort as a whole and the subgroups, it appears that there is little benefit from the Dancing for Health programme in terms of quality of life. Partners appeared to report a decrease in quality of life over the 8 weeks.

In terms of health status there is a mixed picture. Whilst the eight domains measure different aspects of health status and can be reported individually, some are reporting on 'one day' and others how they have been over the past 4 weeks. Physical functioning and role limitations due to physical health contradict each other. Physical functioning reported a reduction in health status and role limitations due to physical health reported an improvement in health status.

### 7.2 Conclusions from the qualitative work

Most dancers were experiencing some form of physical symptoms, including fatigue, dizziness, breathing difficulties and restrictions in mobility. This was also true for bereaved people, many of whom also had health conditions such as arthritis themselves. All dancers therefore appreciated the adaptations to the dance steps and the gentle pace of the classes.

People with incurable illness in particular were aware of the benefits of exercise, and in many cases, dancing was just one of a number of activities they did, making it difficult to ascertain the precise physical benefits of the dancing programme. However, all reported their enjoyment of the dance classes, and in most cases, this meant that they were more likely to attend Dancing for Health than other exercise activities.

Dancers valued the opportunity to socialise, and viewed classes as a distraction from thinking about illness or bereavement. This was particularly beneficial for those who lived alone, or who had become isolated through caring for a loved one for a long time.

Many dancers attended classes alone, but valued the opportunity to socialise with others in similar situations. All appreciated the connections during the class, and a small number had met up outside the class too.

The qualitative work demonstrates that the Dancing for Health programme, specifically tailored for people with health conditions, can be a positive and beneficial way to increase exercise and foster social connections for bereaved people and those with incurable illness.

### **7.3 Limitations and recommendations**

The initial programme lasted 40 weeks, but there was no requirement for dancers to attend every week. Dancers signed up to the programme in six weeks blocks. A small number of participants started at the beginning and were still attending at the end, but many more began attending part way through the programme, and several only attended for a few weeks.

Studying this group of people is difficult due to the nature of the diverse health problems that are inherent with this population. In future studies the recommendation would be to include more people as attrition is a problem however the size of the room dictates the maximum number of participants. Dancers signed up for 6 weeks at a time through Clifford House and we expected that we would have new participants to take part in the study however the same dancers continued to sign up meaning that our total numbers were limited due to space and programme capacity. We were not in a position to prevent this nor would we have wanted to prevent their continued enjoyment of the programme.

Only those participants who were attending towards the end of the programme were invited to take part in an interview, and we have no record of the reasons for non-attendance of people who only attended for a short time.

We hadn't originally planned for partners or bereaved people to take part in the study as we were under the impression Clifford House was solely for people with an illness with no cure. It is unclear how to subdivide participants when not all who attend Dancing for Health have an illness with no cure but do have their own health issues. It is not recommended to aggregate results of ill, bereaved and partners together. It is possible that the results confound each other. We recommend that subgroups be analysed separately with larger numbers.

The FACT-G disease specific cancer scale was chosen to measure quality of life as there was an assumption prior to starting the programme that the majority of the dancers would have a diagnosis of cancer. This was not the case and therefore the FACT-G was not appropriate for many of the participants.

A number of participants discontinued the classes but we did not ascertain the reasons for this.



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