

“Here everyone is the same”- A qualitative evaluation of participating in a Boccia (indoor bowling) group: innovative practice

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Abstract

This qualitative study explored the impact of a Boccia (modified indoor bowls) group on the lives of people with dementia and their carers. Semi-structured interviews with people with dementia (N=6), carers (N=10) and the group organisers (N=6) analysed using thematic analysis revealed four main themes. ‘The struggle of being a carer’ was relieved by participating in the group and benefiting from the caring support and social aspects of “This group is a family”. “The unique nature of Boccia” helped it to provide physical and mental stimulation as well as being an inclusive and enjoyable group. These aspects contributed to many participants describing the group as a Dementia friendly environment where “Here everyone is the same:” treated as equals, without feeling hindered or defined by dementia. Boccia appears an exciting initiative but further research is needed to see if these findings can be replicated with other groups. (146 words)

Keywords

Boccia, dementia, dementia friendly, exercise, people with dementia

Dementia poses personal and social challenges for people with the condition and their families. One study reported that fewer than 50% of people with dementia felt part of a community because of stigma and the non-dementia friendly nature of society (Burgener et al., 2013). Many non-pharmacological interventions focus on uniting people with dementia and their families/carers in mutually stimulating and enjoyable activities. Participation in physical exercise can help offset physical decline and dementia (Perez and Cancela Carral, 2008) and offer the opportunity to rehearse old skills and develop new ones (Bowes et al., 2013). Exercise does not have to be complex or overly strenuous to be of benefit. Activities undertaken together with carers or family members, e.g. outdoor walking, may provide multiple benefits including enjoyment, shared experience, improved mood, and a meaningful sense of routine (Cedervall and Aberg, 2010, Malthouse and Fox, 2014).

Boccia, a modified form of indoor bowls, is a team game, which involves throwing coloured balls at a target ball (jack) from a seated position. The game was initially

designed for players with cerebral palsy but is now played by people with a range of disabilities (GB Boccia, 2015) and there are several groups in the UK for people with dementia and their carers/families. The authors of this paper worked with a local group, established in partnership between the Indoor Bowls Centre and the town's Dementia Carers group. This qualitative study aimed to explore the Newark Indoor Bowls Boccia group as a dementia friendly initiative for people with dementia and their carers.

Study aims were to:

- Explore the perceived benefits of the Boccia group for people with dementia and their carers
- Identify aspects of Boccia which contribute to its success
- Investigate what makes for a dementia friendly environment.

Method

Participants were attending the Newark Indoor Bowls Club Boccia group and (a) had a diagnosis of dementia, or (b) were caring for someone with dementia, or (c) were an organiser/facilitator of the group. Exclusion criteria from the study were an inability to speak English and/or insufficient attention to play Boccia or participate in an interview.

Ethical approval was received from Nottingham University Medical School Research Ethics Committee (ref: D11082015 SOM IMH BMedSci). Informed consent to observe the group and interview individual participants was obtained before the start of the study. Where a person lacked capacity to give consent, a personal consultee (their carer) was approached regarding permission to carry out observations. Capacity was assessed through discussion with the group organisers and carers.

The researcher (IO) attended group sessions over a period of six weeks and observed the Boccia games. Semi-structured interviews exploring the participants' experiences of the group were conducted in a quiet side room. Most interviews lasted around 20 minutes; those with people with dementia tended to be shorter as they gave briefer, less detailed answers and responded best to closed or focused questions (de Vries, 2013).

All interviews were recorded, transcribed verbatim and pseudonymised prior to analysis by the researcher (IO). The researcher's observations and general impression of the group dynamic were recorded as field notes. Interview transcripts were analysed using thematic analysis as this approach enables the researcher to explore for themes both inductively from the data itself and deductively based on theory and research (Braun and Clarke, 2006). It also allows the use of field notes to help create a broader picture from

the data (Crowe et al., 2015). Analysis proceeded iteratively, and was refined in collaboration with another qualitative researcher (CB). Themes were defined and coded, following accepted guidelines (Boyatzis, 1998). Inter-rater reliability of coding was also assessed: 96% inter-rater reliability was achieved: scores >70% are considered acceptable (Boyatzis, 1998).

Results and Discussion

Interviews were conducted with, and observations made of, six people with dementia (3 male, 3 female), ten carers (6 male, 4 female) and six organisers (4 male, 2 female) from the group.

Thematic analysis of the data revealed four major themes and four subthemes (Table 1). After six sessions no new themes were emerging suggesting data saturation.

- Table 1 about here -

The unique nature of Boccia

Boccia was greatly enjoyed by all the people with dementia interviewed in the study and some of its unique elements contributed to its popularity. Boccia requires only basic skills and can be enjoyed by anyone regardless of their physical or mental capabilities; thus enabling new members quickly to become involved in the game and the group. Played from a seated position, Boccia requires low levels of mobility. These aspects are summed up in one participant's explanation of why they enjoyed Boccia:

"Well, it's because I can do it" (Sally, Person with dementia)

This theme resonates with a study investigating dance for people with dementia which concluded that part of the study's success was the simplicity of the dances (Guzmán-García et al., 2013);

A distinct feature of Boccia is that the shape of the mats allows the ball to roll in any direction, thereby introducing an element of luck. This minimises differences in the aptitude of the players and creates an element of competitiveness which contributes to participants' enjoyment:

"I think the sport, it's not a sport of skill, it's a little bit of luck, and you don't have any of "Oh they are better than them" it is luck. It kind of levels it out, and from that point of view they are just happy to have a go and participate." (Bill, Organiser)

Carers can often dominate conversations, sometimes even speaking on behalf of the person with dementia (Denning et al., 2013) and whilst this was still evident in some

parts of the group, field notes recorded people with dementia taking a more active role in conversations during and between Boccia games.

Other unique aspects of Boccia contributed to the benefits seen in the two sub-themes described below.

Physical benefit of Boccia

Although less physically demanding than some exercise interventions, the physical exercise gained from walking over to the game and collecting the balls after each round was more than participants would be doing otherwise:

"When they have a game they are certainly more active, they get some exercise, they walk down the far end." (Bill, Organiser)

Playing Boccia also aided the development of motor skills such as the eye-hand coordination described here:

"... it's stimulating all the time. The day group he goes to do it too, so he has practice. He's better this week actually, the eye and hand coordination is great." (Kim, Carer)

Development of physical skills in this way can permit people with dementia to be more active in a manner appropriate to their physical capability (Bowes et al., 2013).

Mental stimulation from Boccia

During the game, people with dementia had to maintain their concentration, waiting to throw the ball until instructed by ball colour, and before throwing considering who had already thrown. One of the organisers described this as:

"Being able to go in a sequence, which I think sometimes is difficult for them. But they are very focused." (Poppy – organiser)

Regular mental stimulation can increase independence and quality of life in people with dementia (Woods et al., 2006), so this aspect of Boccia is potentially highly beneficial.

'This group is a family'

This theme describes an important perceived benefit of the group for its members. Many mentioned the caring and welcoming atmosphere which made it easy for new members to join and feel included. Moreover, carers were able to have a period of respite, while others cared for or played Boccia with their spouse.

"This group is a family, we care for and protect one another, and I've seen some carers out playing Boccia while others are looking after their partner. It's that kind of relationship that's so good." (Tim, Organiser)

People with dementia strengthened bonds with their spouse, and also with their new 'family' in the group: indeed many participants would arrive early to catch up and spend more time with each other. This sense of belonging is likely to increase wellbeing and mitigate depressive symptoms (Brod et al., 1999). The family-like dynamic within the group meant participants could make light of some aspects of dementia. For example, field notes recorded participants' laughter about their memory during the games and the exchange of anecdotes about things they had forgotten or got confused during the week. Humour has been identified as a coping strategy for dementia, allowing people to view their condition in a more light-hearted manner (Clare et al., 2005) and this ability of the group to nurture humour was an additional benefit.

The Social Aspect of the Group

This subtheme underpinned the theme "This group is a family". Both carers and people with dementia described the enjoyment they received from conversing with others and how they valued new friendships.

"Oh socialise that's what it's all about" (Paul, Person with dementia)

For some, this was their only chance to leave the house and interact with others:

"Meeting people. That's the most important. Because when you are on your own it's just the two of you. You lose the art of conversation, you lose everything. In fact your life ends; you just become a carer and nothing else. When you come to a group like this it's brilliant, you spent two hours here. Talk to different people, it brings everyone together and makes their loneliness bearable." (Mike, Organiser/Carer)

This subtheme supports other research findings describing the benefits of social opportunities, both with and without the person with dementia (Melunsky et al., 2015) (Donaldson et al., 1998) (Carone et al., 2014).

Support from the group

This subtheme was integral to the theme "This group is a family". Participants spoke emotively about the support they received and how it contrasted to the perceived lack of appropriate support from other groups and services. One organiser described how:

"They've all got my phone number so if they wake up in the middle of the night and need someone they can always ring me, if they want. You know when you wake up and need to talk to someone, that's why I give my number out." (Ben, Organiser)

Such personalised and tailored support has been shown to be invaluable for people with dementia and their families by other studies (Bruce and Paterson, 2000).

A significant element of this support was the opportunity for members to share experiences. This was especially valuable as most were at different stages of the process. However, being reminded of the reality of the disease and prospects for the future could be painful and challenging:

"I have found it really, really difficult. John is one of the best here and one of the youngest, and it is hard seeing people further down the line than him." (Lucy, Carer)

Other research has indicated that having an opportunity to learn from others, although hard to accept at times, can help practically and emotionally prepare carers for the inevitable deterioration in the condition of the person with dementia (Melunsky et al., 2015).

"Here everyone is the same"

The Boccia group provided a dementia friendly environment where participants enjoyed themselves and felt comfortable. Several spoke of it as the only place where they felt they were treated as equal to others, were not judged because of their condition, nor defined by it, as powerfully described here:

"Here, everyone is the same, other places they won't talk to me because they know I've got this thing" (Jill, person with dementia)

Social environments, rather than their condition, can powerfully restrict social engagement for people with dementia (Kitwood, 1997). Evidence suggests that a key element of creating the fashionably termed 'Dementia Friendly Environment' is to enable people with dementia to feel that they are making a valued contribution (Crampton et al., 2012). Aspects of the Boccia group, e.g. collecting balls after a game, or simply being involved in a conversation, helped with this. Another recognised aspect of creating a dementia friendly environment is addressing the needs of both carers and people with dementia and treating them as a dynamic partnership (Crampton et al., 2012), aspects illustrated by these themes.

The struggle of being a carer

Perhaps unsurprisingly, several carers discussed the previous themes in the context of their struggles as a carer. They described feelings of frustration: with the person with dementia for forgetting things, with the enforced restrictions on their lives from being a carer; but also with themselves when they lost their temper. The grief at the gradual loss of their partner's identity was poignantly summarised by one carer as:

"Dead before dying" (Bob, Carer).

Strengths and Limitations

This study describes the benefits of a form of group-based exercise that has not previously featured in the dementia literature. The group was very encouraging of the study and participants were enthusiastic about being interviewed. However, not all comments were totally positive, indicating that we obtained an honest range of views.

The study was only able to look at one group over a fairly short period of time; and the group may not be representative of the whole population so Boccia may not have these positive effects for everyone. It was not possible to measure clinical or other outcome measures in this group so we cannot provide quantifiable evidence of the benefits of Boccia. However, the qualitative data suggest this should be explored in a larger study.

Conclusions

Participation at a weekly Boccia group helped in 'The struggle of being a carer' and benefited the lives of people with dementia and their carers by providing support from the family nature of the group. Some of the unique aspects of Boccia make it an excellent source of physical and mental stimulation for people with dementia and contribute to providing a 'Dementia friendly environment'. The study highlights some of the key features of this innovative group. In particular, participation at least temporarily removes the label of diagnosis, and reduces the restrictions, and the impairments caused by dementia.

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Table 1: Major themes and subthemes

Major Theme	Subtheme
The unique nature of Boccia	Physical benefit of Boccia Mental stimulation from Boccia
"This group is a family"	Social aspect of the group Support from the group
"Here everyone is the same"	
The struggle of being a carer	