Swimming for dementia: an exploratory qualitative study of an (Linnovative practice)

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Abstract

Swimming is a non-weight bearing form of exercise that can be enjoyable and promote physical fitness. This qualitative study investigated a local group established as part of a national dementia swimming initiative. Semi-structured interviews with people with dementia (N=4), carers or companions (N=4) and the organisers and facilitators of the group (N=6) were analysed using thematic analysis. This revealed four main themes: (1) the pleasure of swimming and its benefits as a form of exercise and for building confidence and empowering participants; (2) the importance of insight and empathy in creating a safe and secure experience; (3) the burden-impact of dementia; and (4) how participants valued being part of a group 'all in the same boat'. 'Dementia friendly swimming' appears to be a valuable form of exercise but it requires considerable preparation and support to make it happen.

Keywords

Swimming, dementia, dementia friendly, exercise, people with dementia

Exercise interventions for people living with dementia have attracted increasing interest. Several of these have been shown to be beneficial, including walking, dance and football (Malthouse and Fox, 2014, Guzmán-García, Mukaetova-Ladinska and James-et-al-, 2013, Carone, Tischler and Dening-et-al-, 2016). Swimming offers a non-weight bearing activity which can improve physical fitness and reduce strain on joints compared to land-based exercise. For many people, including those with dementia, swimming will be also be a familiar activity associated with happy memories and thus it may be a very suitable form of exercise (Henwood, Neville, Baguley, Clifton and Beattie-et-al-, 2015). There has been limited research around swimming and dementia, with just one recent controlled trial (Henwood, Neville, Baguley and Beattie-Henwood et al-, 2017). This study investigated a 12-week programme for residents of care homes and reported modest effects in slowing muscle weakness and behavioural and psychological symptoms.

However, this study did not report any data reflecting the experiences of the participants themselves. An interesting finding was the disparity in attendance rates at different participating centres, which suggests that positive attempts to make the sessions accessible may pay dividends.

Therefore, it may be worthwhile examining whether swimming sessions can be offered as 'dementia friendly' and if so, what the components of this might be. Although widely used, the term 'dementia friendly' is not precisely defined (DSDC, 2017); instead, it is usually followed by description of its features (e.g. (Alzheimer's Society British Columbia, 2015) Some recent studies have investigated what elements are important for a dementia friendly community. For example, researchers in York (Crampton, Dean and Eley et al., 2012) identified four key aspects: Place, People, Resources and Networks. In Christchurch, New Zealand, following an earthquake, people with dementia identified as important themes: 'Accessible and accommodating leisure and activities' and 'Accommodating and safe physical environments' (Smith, Gee, Sharrock and Croucher et al., 2016). These studies suggest that good access and a sense of safety and support will be important components of dementia friendly swimming.

The Amateur Swimming Association (ASA, Swim England) has a national project to "enhance the swimming experience of those living with dementia and their carers by improving facilities and removing barriers" (Amateur Swimming Association, 2015). The participating centre in Nottingham was set up in partnership with the Alzheimer's Society and this offered the opportunity to evaluate the project at a local level. A qualitative study would enable us to explore how those involved in the project from pool managers to people with dementia experienced it in their own words; and to examine what may constitute 'dementia friendly swimming'.

The study posed the research questions:

- What impact do the swimming sessions have on the lives of people with dementia and their carers?
- How do the sessions affect the experience of caring for people with dementia?
- How, and in what ways, can sessions become "Dementia Friendly"?

Method

Participants were attending the dementia friendly swimming sessions at Clifton Leisure Centre in Nottingham and had a diagnosis of dementia, or were a companion or carer of someone with dementia, or were employed to organise or facilitate the sessions. The only exclusion criterion was inability to speak English.

Ethical approval for this study was received from the University of Nottingham Division of Psychiatry & Applied Psychology Research Ethics Sub-Committee (ref: 307). Informed consent to observe the sessions and interview participants was obtained prior to the first session attended. Personal consultees (a carer) were approached for permission to observe the sessions if a person lacked capacity to consent. Capacity was assessed through discussion with the carer.

The researchers (TH) and (MS) attended swimming sessions over a period of seven weeks. Semi-structured interviews exploring participants' experiences of the sessions were conducted by one of the researchers in a quiet side room. Most interviews lasted around 17 minutes; shorter interviews tended to be with people with dementia as they gave briefer, less detailed answers responding best to closed or focused questions (De Vries, 2013).

All interviews were recorded, transcribed verbatim and pseudonymised prior to analysis by the researchers (TH & MS). The researchers' observations and impressions of each session were recorded as field notes. Interview transcripts were analysed using thematic analysis to allow the researchers to explore for themes both inductively from the data itself and deductively informed by theory and research (Braun and Clarke, 2006). It also permits the use of field notes to create a broader picture (Crowe, Inder and Porte et al., 2015). Analysis was iterative and refined in collaboration with an experienced qualitative researcher (CB). Themes were defined and coded, following accepted guidelines (Boyatzis, 1998). Inter-rater reliability was assessed and 76% reliability achieved: scores > 70% are considered acceptable (Boyatzis, 1998).

Results and discussion

The dementia friendly swimming sessions were a new initiative and recruitment to the sessions was slow: with a maximum of six people with dementia attending the first seven sessions. Although everyone attending the sessions was willing to help the research, two people with dementia lacked capacity to consent to be interviewed. Interviews were conducted with four people with dementia (two male, two female), four carers/companions (four female), and six organisers/facilitators (one male, five female). Two organisers were not directly involved in running the sessions and so did not attend any of the observed sessions, while other participants varied in the number of sessions attended (range from one to seven).

Thematic analysis revealed four main themes and five subthemes (see table 1).

Table 1. Themes and subthemes

Theme	Subtheme
"It's been absolutely brilliant"	Swimming for exercise
	Confidence and empowerment
Insight and empathy	"You're safer you feel more secure"
Burden-Impact of dementia	
"In the same boat"	Creating a support network
	"It's nice to have a break"

"It's been absolutely brilliant"

This powerful *in vivo* theme underpinned the interviews and describes how much all the participants enjoyed the sessions as explained here:

This is consistent with reported findings from other types of exercise project involving people with dementia (Guzmán-García et al., 2013, Carone et al., 2016).

Subtheme: Swimming for exercise

Part of the pleasure in swimming derived from it being good exercise. Carers valued this aspect anticipating it would help with agitation and restlessness as expressed by one carer:

'Giving him the exercise, and will hopefully knock him out for the afternoon. And not let him wear the carpet out walking up and down, up and down.' (Maggie, Carer)

Field notes also echoed this, recording that carers encouraged the person with dementia to keep swimming and to utilise time in the pool for exercise. Restlessness and pacing are common behavioural and psychological symptoms of dementia (BPSD) and can be difficult symptoms for carers to manage (<u>De</u> Oliveira, <u>Radanovic</u>, <u>de Mello</u>, <u>Buchain</u>, <u>Vizzotto</u>, <u>Celestino</u>, <u>Stella</u>, et al., 2015). Preliminary evidence from the Australian

[&]quot;Yeah it's been absolutely brilliant" (Ruth, Person with dementia).

Watermemories studies suggests swimming can improve both BPSD and mood (Henwood et al., 2017, Henwood et al., 2015) and this theme supports those findings.

Subtheme: Confidence and Empowerment

Enjoyment of the sessions also came from the confidence and feeling of empowerment they gave. Although predominantly described by organisers and facilitators it was also mentioned by people with dementia. For example one participant who was a particularly strong swimmer described how he is normally shy and reserved but the sessions gave him the opportunity to develop his confidence and help other participants with their swimming:

'...I felt sort of like... confidence in myself ... to encourage her to keep going.' (Steve, Person with dementia)

The importance of being able to make a contribution has been highlighted in other studies (Ovenden, <u>Dening and Beer-et-al.</u>, 2016) and recognised as an important component of creating a 'Dementia Friendly Environment' (Crampton et al., 2012).

Insight and Empathy

Interviews revealed that organisers and facilitators showed empathy and insight into the struggles faced by people with dementia enabling them to tailor their support for the sessions as described by the instructor here:

"..you can't hurry anything and I think you just have to be very flexible in your approach.." (Emma, Swimming Instructor)

Field notes also recorded an example of staff working effectively to calm one participant with dementia when he became agitated during the swim.

Of the councils participating in the ASA dementia swimming initiative, Nottingham was the only one working in partnership with the Alzheimer's Society to aid recruitment. All participants who attended these sessions were recruited in person, and at the sessions they were supported by an experienced Alzheimer's Society support worker. This suggests the importance of personal contact with trusted staff and resonates with findings from other studies on the importance of trusted skilled staff (Carone et al., 2016, Griffiths, Dening, Beer and Tischler-et al., 2016).

Insight and empathy had ensured that adaptations were made to the leisure centre prior to the sessions to ensure it was dementia friendly. These included features such as more obvious signage and easy access steps as described here:

"..they have made a difference in terms of putting pop up banners they weren't there before so you use to have to actually verbally navigate someone down to the changing rooms but they've put the feet on the floor now to actually say 'just follow the feet around'.." (Jess, Alzheimer's Society Support Worker)

The alterations made before the start of the sessions and the accessibility and location of the leisure centre link to the 'place' requirement of 'The Four Cornerstones' model for creating a dementia friendly environment (Crampton et al., 2012).

Subtheme: "You're safer you feel more secure"

This subtheme reveals how the insight and empathy shown by those organising and facilitating the sessions created an environment in which people with dementia and their carers could feel safe and secure as described here:

"...if there's somebody in the pool with you....it's more instant than somebody running off to say 'I need to get some help!'..." (Ruth, Person with dementia)

People with dementia can lose confidence following a diagnosis and this theme suggests Nottingham City Council are achieving their website's claim for these sessions to provide a "safe and supportive environment". The 'People' requirement of 'The Four Cornerstones' model specifies how it is essential that the needs of people with dementia are recognised within the community (Crampton et al., 2012).

The burden impact of dementia

The <u>burden impact</u> of dementia pervades all the interviews. Relatives not only have to deal with the <u>burden responsibility</u> of caring for someone with dementia but also with the impact dementia can have on their relationship. One carer described feelings of 'losing' her husband as a result of dementia:

'...I've actually lost the person I've loved all my life and um it's very very painful.' (Lucy, Carer)

Carers explained how changes in behaviour brought on by dementia are not understood by the general population, leading to awkward situations and as a result their withdrawal from society:

"..with his inappropriate behaviour he tells people they're fat um and things like that and it became inappropriate really to take him to a public session.." (Lucy, Carer)

Field notes collected during the study detailed how members of the public swimming alongside the dementia session sometimes had very negative reactions towards the people with dementia as described here:

".... neither session have we had a very positive response from the swimmers (members of the public).." (Jess, Alzheimer's Society Support Worker)

One participant however, made the point that it's not just members of the public who can be discriminatory:

".... but then you get some people that just brick wall you and just don't want to know. But there are also people with Alzheimer's who don't want to know." (Ruth, Person with dementia).

This <u>burden-impact</u> is increased by the perception of there being little help or support available as one carer explained:

'There's a lack of funding there's, there's nothing out there for people' (Maggie, Carer)

Poignantly this perception was despite the fact all participants who attended the swimming sessions were recruited from local support groups in Nottingham; and so arguably they were clearly receiving some support.

"In the same boat"

This theme demonstrates that, for many participants, meeting people in a similar situation as themselves was one of the most important benefits of the sessions.

'Because, because it's sociable ... that's what it's all about ... people in the same boat as what I am with him...' (Alice, Carer)

This is in accord with findings indicating that the social aspect of an exercise group for both people with dementia and their carers is particularly important (Carone et al., 2016, Guzmán-García et al., 2013, Ovenden et al., 2016) and research suggesting people with Alzheimer's disease felt more comfortable participating in activities with others who understood their problems and whom they felt they could identify with (Malthouse and Fox, 2014). Furthermore, this theme resonates powerfully with the theme "we're all thrown in the same boat ..." identified in a qualitative analysis of peer support in dementia care (Keyes, Clarke, Wilkinson, Alexjuk, Wilcockson, Robinson, Reynolds, et

al., 2016). One carer described how speaking with someone in the same situation reduced her feelings of isolation:

'You've got somebody to speak to in the same situation like I said and you don't feel so isolated. So erm, that's how. So it makes you feel better, it makes you feel happier about things.' (Maggie, Carer)

For the participant above and many others, meeting other carers at the session provided some relief from the well documented feelings of loneliness experienced by people with dementia and their carers (Adelman, Tmanova, Delgado, Dion and Lachs, et al., 2014). However, such feelings are personal and subjective and to assume the sessions would have a positive impact on everyone would be naïve. Indeed meeting others at an earlier or later stage of dementia may be upsetting. Perhaps this explains why one carer highlighted why she didn't want to meet people in a similar situation:

'I don't really want to meet a lot of other people with the same problem because I'm trying to get away from the problem.' (Lucy, Carer)

Subtheme: Creating a support network

Meeting people in a similar situation allows participants to form new relationships and develop an informal social support network. Peer support provides an opportunity to share coping strategies and form new relationships when individuals may have previously felt lonely and isolated (Keyes et al., 2016). Indeed, informal support networks are associated with reduced depression and burden-difficulties-in-for carers (Morris, Morris and Britton et al., 1988). The weekly swimming sessions were facilitated by an Alzheimer's Society support worker who acknowledged the importance of building this support network:

'And an- you realise how you know i- important it becomes when they start to exchange numbers for example and they're phoning each other up to check who's going ... and they're car sharing and things and that you know...' (Jess, Alzheimer's Society Support Worker)

This subtheme was unexpected as typically swimming does not offer time for interacting with others and establishing new relationships. However, field notes also recorded participants engaging with each other. For example, all participants (including staff) were observed standing in the shallows talking or engaging during one session and participants were recorded gathering in the leisure centre café area after each session.

Subtheme: "It's nice to have a break"

Sessions and their informal support provided a chance to experience a small amount of freedom from caring and some relief from the <u>burden-duties</u> of caring as described here:

'You've got that bit of freedom off... don't know how you can put it really... you feel a little bit more light hearted ... than heavy. Yeah it's good.' (Alice, Carer)

Our field notes also reflected that the structure of the sessions often meant that the coach was able to occupy and look after a person with dementia whilst the carer had an opportunity to swim on their own.

Strengths and limitations

This study provided insight into the thoughts and feelings of participants of dementia friendly swimming – an area of limited research. The researchers (MS and TH) were present during the sessions which allowed them to build rapport with participants and gain access to a range of views. Also, their field notes could be used to provide further evidence to support the themes. Although interviews with people with dementia were often brief they provide valuable insight into their thoughts and feelings regarding the sessions.

Despite the range of interviewees, this study may have benefitted from a larger sample size as data saturation was not achieved; with the last participant providing a contrasting view. However, all participants with capacity were interviewed. Data collected in this study may be particular to these participants and further research is needed to explore if they are generalisable to the wider population.

The dementia swimming project was a new and innovative initiative. As sessions took place, it was evident that changes developed from the experience Further study is needed to explore if these findings can extend to future participants and to look for quantifiable evidence of the benefits of dementia friendly swimming.

Conclusions

Swimming sessions reduced the burden of dementia by providing carerssense of responsibility felt by carers, providing them with a support network and the opportunity to have a break from caring while with others in the same boatsimilar circumstances. Swimming itself was enjoyable for everyone and provided people with dementia the chance to exercise as well as giving them confidence and empowering them. Essential to the sessions being dementia friendly was the insight and empathy shown by organisers and facilitators which enabled participants to feel safe and secure. This study's findings suggests the potential of the innovative practice of making swimming dementia friendly.

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