

Football and dementia: a qualitative investigation of a community based sports group for men with early onset dementia

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Abstract

This study investigates the impact of a weekly group providing sport and physical activities for men with early onset dementia established by Notts County Football in the Community (NCFC). There were three aims: investigate the effect of early onset dementia on individuals with the condition and their carers; examine perceptions of current levels of service provision for people with early onset dementia; and analyse the impact of the group. Men with dementia (n=5) attending the sessions, their carers (n=5), NCFC coaching staff (n=5) and people organising/facilitating the sessions (n=5), were interviewed. Semi-structured interviews explored the participants' experiences of dementia, their opinions on current service provisions and on the sessions. Data were analysed using thematic analysis. Four main themes were found: loss related to the condition of dementia and its impact on relationships ('Loss'); lack of age-appropriate services for people with early onset dementia ('Lack of Resources'); enjoyment and positive anticipation related to the group for all involved ('Enjoyment and Anticipation'); and 'the Notts County Effect' which attributed the success of the sessions to the strong brand of the football club, and to personalised service in a "dementia-free" environment. The NCFC sessions provided a safe low-cost intervention with positive effects upon quality of life for both people with early onset dementia, their carers and the staff involved. This suggests that the service may be valuable to a wider range of people living in different areas

Keywords

Dementia; early onset dementia; football; men; quality of life; sporting activities.

Introduction

The incidence and prevalence of dementia have risen worldwide over the last few decades. There were an estimated 800,000 people with dementia (PWD) in the UK (Department of Health, 2013) with an estimated cost of 17 billion per year (Mashta, 2007). Among these, there are around 15-21,000 people with early onset dementia, which is characterized by the development of symptoms before age 65 (Harvey, Skelton-Robinson, & Rossor, 2003).

Owing to the smaller numbers of people affected, there has been limited research on people with early onset dementia compared to those with late onset dementia (Harris et al., 2004). The National Institute for Health and Care Excellence (NICE) guidelines state that no patient should be excluded from any service due to their age, and recommended that specialist multidisciplinary services should be developed to meet the needs of people with early onset dementia (NICE, 2012). However, small-scale studies indicate that some existing specialist early onset dementia services across the UK may fall short of these guidelines. For example, patients may experience significant delays in diagnosis (Williams, Cameron, & Dearden, 2001), there may be a lack of age appropriate day services for people with early onset dementia, and their family members often express a wish for services such as befriending to be introduced in their area (Sperlinger & Furst, 1994).

Family members of people with early onset dementia are at higher risk of developing feelings of isolation, psychosocial problems, financial difficulties and family problems compared to the general population (Henry Brodaty & Donkin, 2009). Carers also have increased levels of involvement in the care of people with early onset dementia compared to family members of people with late onset dementia, and therefore may require higher levels of support (Roach, Keady, & Bee, 2012). There is good evidence that family members benefit from meeting and talking informally to one another. Studies have shown that peer support (e.g. through support groups or meeting informally) and clear communication (e.g. about diagnosis and available support and services) are valuable in helping carers (Willis, Chan, Murray, Matthews, & Banerjee, 2009).

Increasingly, non-pharmacological interventions are being utilized in the treatment and management of dementia (Department of Health, 2009). These include an emphasis on exercise and participation (Heyn, Abreu, & Ottenbacher, 2004). Football is a novel and emerging intervention in dementia care. Although there is no existing literature on the benefits of playing football on symptoms or quality of life in dementia, some research does suggest that football-related activities may have a positive impact on mental health. Football reminiscence has been shown to have some positive benefits in men with dementia. The researchers found increased sociability, confidence and communication in people with dementia after the reminiscence sessions (Schofield & Tolson, 2010; Tolson & Schofield, 2012). Further studies found that if people with dementia were interested in football prior to their diagnosis they could be engaged in conversations about the 2010 World Cup, and that they had memories of key football events such as the 1966 World Cup (Solari & Solomons, 2012). In relation to more general social issues, a review of government and local football initiatives found that the sport could be used to bring communities together in order to tackle important issues such as mental ill-

health, racism and educational problems. The idea underpinning such initiatives originates from the concept that football is an almost universal interest that brings people together (McElroy, Evans, & Pringle, 2008). Furthermore, a programme consisting of twice weekly football sessions carried out with a group of men with schizophrenia reported improvement in fitness and coordination and self-reported improvement in the participants' quality of life (Battaglia et al., 2013). Other research projects looked at the role of exercise in the management of depression and found positive results, which is promising as 20-60% of people with dementia suffer from the condition. A literature review of the role of sport in the management of depression found evidence that exercise protects against depression and is an effective adjunctive intervention in the treatment of mild to moderate forms of the condition (Rimer et al., 2012).

Notts County Football in the Community (NCFC) has a successful history of providing football coaching to tackle various social and health-related issues. NCFC run numerous sports sessions targeted at various members of the local community such as those with visual impairment, intellectual disabilities and young people from disadvantaged backgrounds. In 2012 they introduced new sessions for men aged 45-65 with early onset dementia in partnership with the Alzheimer's Society. The programme consists of 1.5-hour weekly sessions and includes various physical activities such as badminton, bowls, basketball as well as football. It also provides refreshments and an area for family members to sit and converse with each other.

This study aimed to explore the needs of people with early onset dementia and the impact of football and sports activities as a non-pharmacological intervention, on both the individual and their family members.

Method

Participants were purposively recruited from the NCFC project. At the time of the study there were twelve people with early onset dementia who attended the sessions, seven family members and twelve coaching staff. Twenty people were approached and gave written informed consent to be interviewed. These were people with early onset dementia (service users with a diagnosis of early onset dementia attending the NCFC group n=5); family members (all wives of people with early onset dementia, n=5); and staff (NCFC coaching staff facilitating the sessions (coaching staff) or external paid members of staff involved in the care or delivery of services for people with early onset dementia (external staff) n=10).

People with early onset dementia were interviewed either individually (n=3) or in pairs (n=2). This was due to their individual needs and requests, as previous research recommends a person centered approach when interviewing people with dementia (Dewing, 2002). In line with this, people with early onset dementia were asked if they would like a chaperone during the interviews; all except one requested and obtained a chaperone. Staff and family were interviewed in focus groups. Focus groups were preferred to one-to-one interviews as this technique allows participants to explore, introduce and clarify their own ideas and concepts

in ways that are not always possible in one-to-one interview settings; this technique also encourages participation from more reluctant or less confident participants (Kitzinger, 1995).

All interviews were conducted by the lead author (LC) with at least one observer (TD or VT). Throughout the study, the lead author (LC) kept a reflective diary in order to reduce researcher bias and increase transparency (Ortlipp, 2008).

All people with early onset dementia were white British males. Their ages were between 59-64 years (mean = 61 years). Interviews lasted on average 20 minutes, ranging from 16-29 minutes. The interviews focused on their experience of early onset dementia and their views about the sessions run by NCFC. Interviews tended to be brief as they took part during the NCFC sessions and participants were keen not to miss the sporting activities.

Family members were interviewed as two separate focus groups, with one group having 2 family members and the second group having three. All family members were white British females. Their ages were between 57-69 years (mean = 62.8 years). Interviews lasted 46 and 58 minutes. The interviews focused on the impact of both a diagnosis of early onset dementia and the impact of the NCFC sessions.

External staff and coaching staff were interviewed as two separate focus groups. The coaching staff were employed by NCFC and were all young adults (four males and one female) aged 17-30 (mean age = 22.4 years). All were white British in background. The external staff consisted of two employees of the Alzheimer's Society (who work directly with people with early onset dementia), an occupational therapist from the Nottinghamshire Healthcare NHS Trust Working Age Dementia team and two management staff from NCFC. The external staff interview lasted 49 minutes and the coaching staff interview 18 minutes, which reflected that external staff had more expertise in dementia and in the overall context of the programme.

The interviews focused on current service provision for people with early onset dementia and the organization and impact of the NCFC sessions.

Ethical approval

Ethics approval was obtained from The University of Nottingham Medical School Ethics Committee (ref OLT11072013 CHS Psychiat), and permission to undertake the study was obtained from NCFC. Before approaching any of the participants in the group, we asked family members and staff if they were likely to have capacity to consent to interviews. All people who were interviewed signed written consent to take part. All participants approached had capacity to consent for interview and any individual who did not have capacity was not recruited for this study. All interviews were audio recorded and transcribed verbatim by an external transcription company.

All transcripts were anonymized, this included individual names and ages at request of the participants. All names included in the results section have been changed to protect identity. No data software was used for the analysis.

Analysis

Qualitative research is often used when collecting sensitive and in depth data that are required for a thorough analysis of complex situations such as life events, quality of care, service evaluations and causes and effects of illness (Wray et al., 2007). Thematic analysis was selected because deemed the most appropriate form of analysis, as it provided the highest level of flexibility and enabled the researcher (LC) to explore in depth the emotions and complexities discussed in the interviews. Such level of exploration would have not been possible using quantitative research (Joffe and Yardley, 2003).

Braun and Clarke's six phase model for completing thematic analysis was utilized in this study (Braun and Clarke, 2006). This model has been summarised in Table 1.

==Table 1 about here==

An informal follow-up group was conducted where themes and quotes extracted from the transcripts were discussed with five of the participants for verification. Data saturation was achieved, as no new themes emerged from the last interviews. However, all transcripts were analyzed and included in the results to ensure that no new themes were missed (Marshall, 1996).

Results and Discussion

Four themes were identified from the data analysis. These are summarised in Table 2 and evidence for each theme is discussed in turn. Note that pseudonyms are used to protect participant anonymity.

==Table 2 about here==

Loss

The first common area of discussion was the impact that a diagnosis of dementia has on both the individuals' and their families' lives. Dealing with such an event was described as a big shock and adjustment. Participants spoke about dealing with the label of dementia, and one even mentioned his attempt of researching the diagnosis on the Internet and finding only negative information about it. Others spoke about having the word 'dementia' attached to them, and another one mentioned that he was unable to adjust to the idea of not being able to control the disease:

“Just got a letter through, you know, saying, 'Would you like to come to the Alzheimer's one?' knowing that I was one of them. And that made a real big difference, you know” (Bob, person with early onset dementia)

“I should be able to deal with it. But I cannot find the answer” (Fred, person with early onset dementia)

For family members a prominent concept that emerged was the process of the emotional and physical change from spouse to carer:

“At times you think you are more of a carer than a wife, in many aspects” (Jill, Wife)

As well as the emotional and physical change in the relationship, the men with dementia also spoke of the impact a diagnosis of EOD has on the sexual side of their marital relationship

“Um, there's no [sighs] - there's not a proper loving relationship any more, between me and my wife. Um, there's no sexual relationship between me and my wife. Um, because I was angry. I'm still angry. And, um, I'm not able to deal with it and overcome my emotions particularly well.” (Fred, person with early onset dementia)

Participants spoke of the high levels of both physical and emotional care they provided for their husband:

“He doesn't make any, any drinks at all now, um, I think because he's, obviously he's getting worse as months go by...with the spatial awareness he only eats off one part of the side of the plate. So while he's not looking I'll spin the plate around and then he starts eating the part that he left” (Jill, Wife)

As well as the wives commenting on the levels of care they provide for their husbands, the men with EOD recognize themselves that their symptoms often impacts on the activities they used to be able to enjoy with their spouse:

“she's, um, she likes, she likes the, er, going out but it's getting too much for her, you know, now. I mean, she's younger than me” (Bob, person with early onset dementia)

This high level of care that the spouses provide inevitably leads to feelings of frustration and despair, which they feel guilty for expressing:

“I don't always deal with it well, I sometimes do lose my temper and as soon as I've lost it and I've looked at him, and he's looked at me like to say what have I done?” (Helen, Wife)

As well as their own frustration, the participants also spoke about their husbands' frustration with life after the diagnosis of early onset dementia:

“Eddie can get, when he gets upset or he's frustrated, it sort of makes it like you're treading on eggshells emotionally and everything. Um, and that can cause rows, in a way” (Donna, Wife)

And the people with dementia themselves spoke of how often they take out their frustration they experience with EOD on their wives:

“Psychologist at, er, St Francis Uni: he came to see me, and he says, he agreed. He says, 'Yeah, you need some way of escaping.' And I said, 'Well, I need a punchbag.' I says, you know, um, some form of punchbag. I said, 'I need to get rid of my frustrations.' Because at that point, you know, you do take it out to your nearest and dearest.” (Fred, person with dementia)

Support from family and friends was found to be lacking, which increased the feelings of isolation in the carers:

“we don't really get a lot of support from family. And there's only our son and he's, works full-time and.....disappointed with some friends, you know, and I've said about things I'm having difficulty with and that. I, I want them to say, oh well, we'll come over and do it for you.” (Donna,Wife)

However, despite a perceived lack of support from family and friends, the family members outlined how difficult the diagnosis had been on their children, and how their children had struggled to accept their fathers' diagnosis:

“now my son, he just can't, he can't get his head around that someone that was so professional and high up in his job and, you know, did everything, run a massive company and you know what I mean?” (Jill,Wife).

The wives also revealed how they viewed a diagnosis of EOD as almost as if the husband they had prior to EOD had died and describe it as traumatic life event:

“You know, anything that came along in life he'd deal with it; very strong, very capable. And we thoroughly enjoyed - we did a lot of travelling, um, all that, you know, it was wonderful, and, um...So it's - it has a devastating effect, not, not immediately. When you're first told, you know, someone you really care for has got this illness, um, and you look at you think, oh well, he's not too bad, you know, we'll, we'll get, you know.....we'll get by in many years probably. But you don't know how it's going to pan out and for us, two and a half years later, you know, he really, really struggles in, with everything in his day-to-day life. And, um, it, you know, he can't remember what the person he was and when he sees me struggling, sometimes it's like he doesn't really...and I know he, he does care, and this is why I know now how poorly he is. Because he will see me struggling and it won't bother him, and that is devastating for me personally” (Anna, Wife)

“Well, the way I'd put it when someone asked me, I said it's like a bereavement...because you've lost the person that you actually married” (Jill,Wife)

These feelings and experiences described by both the people with early onset dementia and their family members were further echoed during the interviews of the external staff:

“I know we say the term so loosely, 'carer' but, you now, when all is said and done it's their husband, it's somebody that they married all those years ago, that they absolutely love and worship” (Alzheimer's Society, external staff)

Very little research has been carried out on the perspectives and experiences of people dealing with the diagnosis of early onset dementia. However, available research concurs with this study that such a diagnosis requires both a grieving period and the opportunity to find a new identity while dealing with the loss of the old one (Harris, 2004).

All family members spoke about both the physical and the emotional stress that early onset dementia brings and a perceived lack of support from other family members and friends which leads to feelings of isolation and detrition of their marital relationship.

Previous studies have shown that over 80% of carers of people with early onset dementia express frustration and 73% experience feelings of grief and bereavement, and that adverse psychological effects are common, more so in female than male carers, the effects being more marked in younger carers (Luscombe, Brodaty, & Freeth, 1998). Some studies even conclude that carers are the hidden victims of illnesses, in terms of being at risk of physical, mental, emotional, social, and financial problems of their own (Holicky, 1996).

The loss of practical skills caused by dementia ultimately results in partners becoming unpaid carers and thus at risk of developing stress and a sense of burden. The work of unpaid carers, much of which is in support of people with dementia, has been valued at about £119 billion per annum (Buckner et al., 2011); therefore any intervention that reduces carer burden is of great economic as well as personal benefit. Provision of adequate respite services has important effects. For example, the provision of informal respite is less linked to negative feelings of worsening health, than is seen with more formal respite provisions (Ashworth and Baker, 2000); support to family members can help them to care more effectively (Sheldon, 1982); and, if caregivers' stress can be reduced, admissions to hospitals for people with dementia may also be delayed (Brodaty and Gresham, 1989).

A final observation on this theme is that there is some evidence that the perception of loss was somewhat different between the men with dementia and their wives. The men were perhaps less able to articulate all of the things that they had lost, though one did refer to loss of intimacy, and their reactions were characterized by frustration and bewilderment. In contrast, their wives commented more on the aspects of bereavement and sadness that arise from the evolving dementia.

Lack of resources

This theme indicates that participants felt there was a shortage of age appropriate services within the local area.

***It's the age you see, that's, that's the difficulty because Derbyshire, which we apparently come under for mental health, there is lots but it's all geared up for people that are...(Over 65)."* (Anna, Wife)**

This resulted in people with early onset dementia having to utilise services which were intended for use for those with later onset dementia. These services may not meet the needs of those with early onset dementia:

"you are very, very isolated...with them being so young... And when you think they've had an active life working... I mean, you know, John can't grasp that he can't do this and he can't do that, but there's nowhere for him to go. And you don't want to - no disrespect to the eighties and nineties, hundreds, whatever, but you don't want to sit in a day centre with people that have got blankets around their legs and being taken to the toilet, and being fed or, you know, they don't, they don't want that. I don't want it. I won't send him somewhere like that. It's too - it's soul-destroying. (Jill, Wife)

Such services were also noted to be inadequate to support family members of people with early onset dementia:

"I was in a room like this with carers who were the same age as me, but they were there for the parents. I was the only one there that was there for their husband" (Anna, Wife)

And family members felt ill-equipped to deal with any emergencies that may arise due to their loved ones' diagnosis:

"I said I hadn't got the crisis team number, and he says we don't have a crisis team here. So who would I ring, it's not, it's not 24/7?" (Carla, Wife)

Previous studies have highlighted similar problems to those mentioned by the study participants (Delany & Rosenvinge, 1995; Luscombe et al., 1998). This is concerning, especially as we know that appropriate community support can reduce admissions to hospital for people with dementia (O'Connor, Pollitt, Brook, Reiss, & Roth, 1991).

Enjoyment and anticipation.

Both the family members and staff spoke of the enjoyment and anticipation the people with early onset dementia experience due to NCFC sessions:

"But when he got here and he came away it was like a great big weight off his shoulders, like a little boy come out of a shop with a new car, you know, that sort of... 'I really enjoyed that', which is very positive, because he hadn't got much happening other than me in his life" (Helen, Wife)

"She said every morning he gets up saying, 'Is it Wednesday yet? And that's the highlight of his week, you know.'" (Alzheimer's Society, external staff)

As for the family members, the perceived benefits were focused on the provision of peer support:

"They've got no one else to talk to, have they, so they're talking to other people in the same situations as themselves. So, you know, when I've spoken to carers over there, they, you know, they're really, you know, really talkative, you know, not to me, but to everyone that's there, talking about their experiences, and I think it really does help" (Alzheimer's society, external staff)

The people with early onset dementia who were interviewed spoke of both the benefits of physical exercise and the social opportunities the sessions offered:

"I enjoy meeting new people and starting up different sports with people" (Greg, person with early onset dementia)

"I've never played, er, um, badminton before. I played really well. Yeah. Played it all the time. It's really good" (Bob, person with early onset dementia)

The people with early onset dementia also acknowledged and spoke of the benefits they believed the sessions had on their wives:

"And, um, now and again they'll come down here for the latter part of the session, just to see what's going off, and to be able to talk to the other wives and, you know, share problems and, er, y-, give each other support" (Fred, person with early onset dementia)

Interestingly the coaching staff are drawn predominantly from the NCFE academy programme, which provides apprenticeship opportunities to young adults. When asked in the interview what they understood about dementia the replies from the coaching staff showed their knowledge of dementia extremely limited:

“is it when the brain defragments slightly, and the mental age can go backwards, can't it, as well? Um, 'cause I seem to see that quite a bit in a couple of our participants, where they're a bit adolescent and, you know, it's a bit immature at times, things like that. So, um, I know a bit, but I wouldn't say I know everything about it” (Coaching Staff)

“I don't really know much about it.” (Coaching Staff)

“Um, I know some of the basic things but nothing too in-depth about it” (Coaching Staff)

However, despite this the coaching staff both spoke and acknowledged how important the sessions were to the men with dementia in order to improve their memory and mood:

“Like Ben plays a lot of football, 'cause he was an ex-pro and things like that. He loves it, he thrives on it: that was his career. So for him to play a bit of football, again he's reliving that highlight of his life, um, and his memories, so they're bringing memories back, which is what we trying to do. Try and give them something that they can remember, because they've got the tendency to forget things.” (Coaching Staff)

And also to learn new skills in an environment which understands their needs:

“Yeah, and also a lot of these guys might not have played sport when they were younger as well, so it gives them that sort of second opportunity where a lot of people may regret they never took up a sport when they were younger. Um, you know, that it's throwing them back into that - they're on a level playing field with everybody, so it might be, you know, a footballer and a, a cricketer both playing badminton against each other: they've both never played it and they're, you know, they're giving each other a good game” (Coaching Staff)

And finally the importance of social interaction:

“think it's good that, um, 'cause it sort of shows that, you know, they can still do it. That, you know, they don't just have to stay in the house and, you know, be guided, that they can actually do stuff on their own. Um, obviously being overwatched, but I think it just shows that they can still do stuff, you know, despite having it”. (Coaching Staff)

The coaching staff as well spoke of the impact of EOD on the wives and also the importance of the NCFE sessions to them:

“I think it's good for the wives. Because they have to deal with, with their partners having dementia every day, and, um, I talk to a few of them, and this little break of an hour and a half is a massive godsend, where they can go and shop or something - a lot of them go shopping here, so [laughs] - 'cause they talk and things like that, and to give them the break, more, because they have to deal with it every day. I think it's a massive benefit to them, as well as the guys that are taking part who suffer from dementia as well, so - it's affecting two people in the relationship, really, in't it?” (Coaching Staff)

As well as the coaching staff speaking of the benefits of the session on the men with dementia and their wives, they also spoke of how they benefitted from the sessions:

"I think it's good to just have in your background that you can sort of handle activities with people with dementia" (Coaching Staff)

And how they actually enjoyed and looked forward to working with the men with dementia:

"I enjoy doing it. Like, you get to join in with them and it's really good" (Coaching Staff)

"I like the, the people that attend it. Um, down to earth. Um, just people that you can have a general chat with as well as work with" (Coaching Staff)

"I like it 'cause they do a lot of different sports every week, and they all seem to have a smile on their face, which is the best thing about it." (Coaching Staff)

This concept of the NCFC session being of benefit to the coaching staff as well as the men with dementia was also mentioned by the external staff and the men with dementia:

"We've got 25 or so coaches and the ones who work on this always say 'I really enjoy dementia', which they don't say about other projects, you know, they find it quite interesting. And I think it's because they find it interesting they, I think they're benefitting as people from it, and as coaches, that they put more into it" (NCFC, external staff)

"Even the people, you know, like the lads from...er, Notts - ...- um, you know, they interact with us all in there, you know, so it's, it's good two ways. You know, I think they enjoy it as well" (Bob, person with early onset dementia)

All those with early onset dementia stated that they enjoyed the physical exercise that the sessions provided. This coincides with previous research that showed that remaining active is a key aim for people with dementia (Phinney, et al., 2007). Physical activity has also been noted to provide people with dementia with a meaningful routine (Cedervall & Aberg, 2010).

The NCFC sessions provided an opportunity for family members to meet other and socialise. All three participant groups agreed that this was beneficial, and in fact such informal support has been proven to reduce caregivers stress (Locock & Brown, 2010).

The social aspect of the sessions was found to be beneficial not only for the family members, but also for the people with early onset dementia. Studies have shown that meeting people in a similar situation and engaging in activities where people with dementia are accepted and not required to explain their disabilities improves their mood and morale (Mason, Clare, & Pistrang, 2005).

Finally, some of the most surprising quotes mentioned the benefits of the sessions for the coaching staff.

. The finding that the coaching staff also reported increased self-esteem and enjoyment through working with people with early onset dementia is novel, but there is some research consistent with it. Educating young people about mental health problems can help reduce stigma and also increases confidence, empathy and understanding when dealing with mental health in their personal lives (Pierce, Liaw, Dobell, & Anderson,

2010), also, intergeneration-based sessions can produce positive results for both older and younger participants (Creative-Dementia, 2012). The interview with the coaching staff also revealed that it does not take formal training or qualifications to understand the impact dementia has on both the individuals and their families life. Furthermore, its apparent that this is also the case in people understanding how basic interventions such as providing social interaction helps reduce feelings of isolation in people with dementia and how providing respite for family members can be of huge benefit to their psychological well being.

The Notts County Effect

The 'Notts County effect' was a combination of the activity being located within a well-known football club and the opportunity that the group gave people to feel normal within it. It was often described as an important reason why the sessions had been successfully run and enjoyed by everyone.

NCFC have extensive experience in delivering sport sessions to diverse and often overlooked groups in the community, and this has led them to achieve a strong and positive reputation:

“I just think the reputation that we've got as well, in terms of the aspects of different work we do for the health, the disability side and the education side, ...So the n-, having the name, 'Notts County Football in the Community', is a massive advantage as well, for successful projects” (Coaching Staff)

And the men with dementia also commented on the name “Notts County” made them initially interested in attending the sessions:

“And of course then it was to do with Nors Cou-, Notts County and that, which was quite interesting. I know it's for the comm-, community, which is good, really, you know, from that, but, er, it's been - it's been good” (Bob, person with early onset dementia)

A further perceived benefit of having NCFC behind the scenes was that they could provide skilled coaching staff to deliver the sessions:

“I think it's because our coaches are really good, and we've got people who we dedicate specifically to this project who are very skilled; they've got good interpersonal skills, they've got a lot of experience in sports delivery” (NCFC, external staff)

NCFC is a large and well-established organization. This results in their ability to provide a high ratio of staff to people with dementia, which means a higher level of personalised and person-centred care can be offered:

“We have a lot of coaches that we send over, maybe five coaches per session, so there's two participants to one coach. So they're getting very intensive care and I think that is something that participants benefit from”. (NCFC, external staff)

Alongside the above-mentioned experience in the field, having the name of a well-known football team behind the project was also believed to increase people's interest in the project itself and decrease the stigma attached to attending a group:

“The fact that they go there on their own, and it's to do with Notts County, you know. It's not like saying, 'Oh yes, and it's all run by dementia trained', you know, that would be awful for people to be thinking that, that they are, you know, special needs in a way” (Occupational Therapist, external staff)

In particular, the fact that the sessions were an all-male environment, and therefore provided a safe place where people with early onset dementia could interact and bond with other men, was deemed a key factor:

“I think as well a lot of the guys who go and who should be still at work, they're not at work because of this condition and this gives them that kind of environment where men get to hang around together in a manly environment.” (Alzheimer's Society, external staff)

Moreover, the sessions were a “dementia free” zone, and offered the people with early onset dementia an escape from their illness and a chance to feel “normal” again.

“It's brilliant to be able to go and do something normal, not to sit and chat about your diagnosis and how that feels...But actually to just go and do something that's a normal activity, that we can go and burn off some energy and do it in a safe place” (Occupational Therapist, external staff).

“I would hate to be in a situation where there was no support whatsoever, and being so young as myself [slight laugh]. Um [sighs], yeah, it, it'd be frightening to think, if there was nothing available whatsoever. Because, like I said, I was, um, quite suicidal, and, er, had I not had the support that I did get, um, I can see that that probably would've, er, had a different outcome” (Fred, person with early onset dementia)

The feeling that the sessions provided a sense of normality was echoed by the family members:

“I think it makes.....them feel normal, you know...because they have so much in a day that they can't do and get frustrated with...Whereas they're here, they've just, they're just being what they want to be, a group event” (Helen, Family member)

The participants believed that having a well-known football name behind the NCFE sessions stimulated interest. Everton Football Club reports similar success of the reminiscence sessions they provide for people with memory problems in the Liverpool area (Chambers, 2012). This suggests that football can be an effective way of engaging people with dementia in meaningful activity, as a kind of low-cost non-pharmacological intervention.

The interviews showed that the sessions provide a sense of normality for both the family members and the people with early onset dementia. They provide a space for understanding and belonging amongst the family members, and for the people with early onset dementia the group provided an opportunity to forget about their diagnosis, belong to a sports group and even relive their youth. The issue of the potential benefit of an “all male” environment is worthy of attention. Studies have shown that men are generally less likely to engage with services than women, and less likely to willingly discuss their problems (Möller-Leimkühler, 2002). Providing suitable, acceptable environments for older men has included such initiatives as Men in Sheds (or Men's Sheds, see <http://menssheds.org.uk/>) while, in residential care settings, ‘gentlemen's clubs’ can bring about reduced depression and anxiety together with an increased sense of social identification (Gleibs et al.,

2011). In our study, having an all-male environment, together with the “dementia free zone” provided an excellent form of respite, as evidenced by the interviews with people with early onset dementia.

Kitwood (1997) emphasized the importance of putting the PERSON before the dementia; and dementia and citizenship is a current important discourse (e.g. Kelly and Innes, 2013). The NCFC session fits the description of citizenship type model of community based service provision in the sense that the idea that people are engaging and remaining as part of their community. Another important feature in the success of the project is its reciprocal nature, with the coaches getting as much out of it as the men with dementia attending and their families. People living with dementia want to continue to be part of their communities and have active roles. Engagement in normal leisure activities is an important way to combat stigma and support relationships within families, as at such times their spouses can still see and recognise the person that they married or can focus on their capabilities rather than on what that person can no longer do.

In addition, the quality of the coaching staff and the high staff to people with early onset dementia ratio ensures that the sessions are adapted to each individual. Individualized care has been shown to help reduce dementia symptoms (Gitlin et al., 2008).

Having the name of ‘Notts County’, an established football club, also behind the project helps to de-stigmatise the project, and further enhances the concept of a “dementia free zone”. The fact that the sessions were run by sports coaches and not care staff was appreciated by the staff group, who stated that it helped make the people with early onset dementia feel “normal” again. Previous research has found that meaningful non-clinical activities for people with dementia have positive effects for participants (Camic et al., 2014). Normalization of life for people with dementia has been shown to be an important strategy in maintaining a positive mood and enhancing coping strategies (De Boer et al., 2007).

Strengths and limitations of this study

The main strength of the study is that it is the first to explore the views of participants involved in a sports intervention for men with early onset dementia. The findings cannot be generalised beyond those who took part, as the participants were probably not fully representative of the local population, either the general population or people with dementia. However, the people approached for interviews were not pre-selected in any way and to that extent may be presumed to be typical of people with early onset in this community. It is, however, also quite plausible that similar effective models of service could be developed elsewhere in the UK or overseas. We have not examined whether a sport-based activity programme would be equally effective for women, and as the carers in our study were exclusively wives, we cannot say much about any benefits on other generations within the families of people with dementia.

One major strength of this study is that this one of the few research projects where which men with dementia were actually interviewed. There were some limitations in this, as the interviews were relatively short, with one of them being only 16 minutes long, and there were clearly some difficulties for the men in expressing their thoughts in detail. It is also noteworthy that the coaching staff interview was also only 18 minutes, but it was felt that the paucity of content offered meant that the interview resulted in being relatively brief.

However, again it is accepted that could be classed as limitation and possibly a barrier to collecting in-depth data.

Implications for future research

Early onset dementia is a neglected area of research. It is important because of the evidence of the heavy emotional toll on people with the condition and their families. The availability and provision of age appropriate services for people with early onset dementia appears to be an area which requires further development.

Conclusions

Our research yielded four main themes which describe how the impact of a diagnosis of early onset dementia causes a profound alteration of the lives of those with the condition and their families, especially their spouses, who have to adjust to the role transition from wife to carer. Despite the enormous consequences of its diagnosis, there is inadequate service provision for people with early onset dementia, as current services generally target people with late onset dementia. This results in people with early onset dementia and their family members feeling isolated and unsupported. The NCFC sessions provide a valuable activity for men with early onset dementia: a chance to feel normal, to socialise with other males and to play sports. They also provide the family members with an invaluable opportunity to meet others and receive much-needed peer support and informal respite. The sessions also provide both family members and people with early onset dementia a feeling of acceptance, and the opportunity to meet people who share a similar situation, age and diagnosis.

A major contributor to the success of the sessions is the established management of community sports sessions by NCFC. Thus, sessions are run by motivated and well-trained coaching staff who provide sessions that are individually adapted to the people with early onset dementia.

This qualitative study has demonstrated the positive impact of a community exercise programme for people with early onset dementia run by an established football club. The NCFC sessions are an example of an accessible, community based activity that could be more widely utilized in the care and management of early onset dementia. The findings suggest high levels of satisfaction with the service and indicate that it is meeting the needs of this group of individuals with dementia. Further research would be needed to investigate such provision in other areas of the country and with a more diverse mix of participants. Other outcomes, such as delays in hospital admissions or reduced prescription of psychotropic medications could also be explored.

Declaration of interests

The authors declare that they have no conflicts of interest in relation to this work. LC undertook the project for the degree of Bachelor of Medical Sciences at the University of Nottingham. No external funding was received.

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Table 1: Stages undertaken for thematic analysis

Phase	Measure taken
1. Immersing oneself in the data.	Transcripts were read and re-read several times to allow the researcher (LC) to become immersed in the data. Field notes and reflective diary were also read to understand the contextual meaning of the interviews and to become more immersed in the data. Transcripts were also read and checked against the original audio recordings. Initial observations were made on the individual transcripts.
2. Generating initial codes.	Initial codes were derived from the transcripts, and a coding book was produced. Codes were discussed with the fellow researchers (VT & TD).
3. Finding themes.	Initial themes were derived from the codes using a “thematic map” and again the themes were discussed at length with the other researchers (VT & TD).
4. Refining themes.	The themes were distinguished and refined using the concept that “coherence of ideas rests with the analyst who has rigorously studied how different ideas or components fit together in a meaningful way when linked together” (Leininger, 1985).
5. Defining and naming themes.	The themes were defined and named, and each theme had a detailed analysis in order to tell its own story. Emerging themes from the transcripts helped form frame work within which subthemes were identified (Crabtree, 1999).
6. Producing a written report.	A report of the research was produced with an introduction, method, results and conclusion.

Table 2: Themes and subthemes

Theme	Subtheme	Example Quote
Loss	<ul style="list-style-type: none"> • High levels of care • Frustration • Lack of support from family and friends • Decline in people with early onset dementia practical and social skills • People with early onset dementia emotional struggles • Uncertainty over future 	<p>“having a diagnosis and the trauma that that - not for everybody, some people it doesn’t feel that way - but, you know, the grief and loss. It is a sense of loss, and there is a grieving process that people go through. And to have to lose work, to lose those roles in your family, you know, in society, the financial implications, your role in terms of being a grandfather or a father, that changes.” (Occupational Therapist, External Staff)</p> <p>“the past makes me happy and sad, the future I don't know where, I don't know what, I don't know what'll happen, I don't know what'll happen, or where I'll be, or what I'll do, or how we'll cope? I don't know. I don't know” (Anna, Wife)</p>
Lack of resources	<ul style="list-style-type: none"> • Inadequate services • Lack of age appropriate services for People with early onset dementia 	<p>“I'm in my house all day and I'm seeing nobody. It is only the likes of you, this lot, that I get to see and it's depressing.” (George, person with early onset dementia)</p> <p>“I think there's gaps in services, I think nationally as well as locally, certainly what we've seen through the society. So, yes, I think there's still a lot to be done” (Alzheimer’s Society, external staff)</p>

<p>Enjoyment and anticipation</p>	<ul style="list-style-type: none"> • Sense of normality • Increases mood • Physical benefits • Peer support • Improvements 	<p>“with coming here you don't have to explain to anyone and it's lovely. You've got no pressure on you...(Yeah)...you can come here and just...you don't have to sort of, oh I'm sorry, but my husband's got Alzheimer's, you know, or...No, you just, you accept it” (Anna, Wife)</p> <p>“I wanted something physical to make me sweat and think about something else and, um, so this covers a lot for me. And it's not just a matter of getting the group. It's getting the physical exercise, the mobility; it's getting, um, mental release of the pressures that's at home” (Fred, person with early onset dementia)</p>
<p>Notts County effect</p>	<ul style="list-style-type: none"> • Reputation • Skilled staff • High ratio of staff to people with early onset dementia • Male environment • Personalised sessions • Dementia free zone 	<p>“I guess a lot of the success of it is that most of the coaches are in their twenties, a lot of them are men who are quite fit, and it's a quite different, sort of, environment to a lot of the services that they take part in. And what we try and do is we're quite good at motivating people and giving people the, sort of, this sort of aspirational thing, you know, whether it's a teenager or a five year old or someone with dementia” (NCFC, external staff)</p> <p>“I think as well a lot of the guys who go and who should be still at work, they're not at work because of this condition and this gives them that kind of environment where men get to hang around together in a manly environment.” (Occupational therapist, external staff)</p>