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# **Sporting Identity, Memory and People living with Dementia: Opportunities, challenges and potential for oral history**

## **Introduction**

Dementia is a syndrome caused by a large variety of progressive disorders that affect the brain and cognitive functioning over time, the most common being Alzheimer's Type Dementia. People living with dementia experience a wide range of changing symptoms and pathologies including impaired learning and recall, difficulty with speech and understanding, changes in behaviour and reduced ability to undertake activities (Alzheimer's Disease International, 2014). Adjustment to these symptoms is complex, and dementia is experienced differently by different people (Brooker & Latham, 2016). Scientific understanding of the syndrome has increased but disease modifying pharmacological interventions remain elusive (Stella *et al*, 2015). Nonetheless, evidence suggests that people should have access to accurate diagnosis at a time in the disease process when it can be of most benefit to them (Brooker *et al*, 2014). The term *timely diagnosis* is used to reflect this. The diagnosis can help people and their families make sense of what is happening and make lifestyle changes and plans for the future. Timely diagnosis is now part of all National Dementia Strategies including the World Health Organisation Action on Dementia (WHO, 2017). Part of the emphasis of those plans being upon the importance and significance of neighbourhood and community, and the strength people with dementia retain for emotional memory (Dementia Café, 2018; Guzmán-Vélez *et al.*, 2016). How this is enacted in people's day-to day experience and in research into this remains challenging. Various psycho-social interventions are available (Donkers *et al*, 2017; Churcher-Clarke *et al*, 2017) and the importance of putting the person with dementia at the heart of any intervention, and prioritising their sense of personhood is recommended (Kitwood & Brooker, 2019).

Historically, people with dementia have found themselves regarded as passive passengers within society, locked into journeys characterised by paternalism and inertia (Bond, 1992;

Peel, 2014). In more recent times this oppressive positioning has been challenged not least through the efforts and advocacy of people with dementia themselves (Swaffer, 2016, Mitchell, 2018; Oliver, 2019). The numbers of people living with dementia continues to increase as populations' age and people are being diagnosed at much earlier stages in the disease trajectory. This affords an opportunity to gather oral histories directly from people living with dementia in a way that would not have been conceptualised previously. This also fits well with the concept of social citizenship, which is applied to the context of living with dementia to emphasise the importance of the active participation by people with dementia within their lives and society (Bartlett, 2016; Bartlett & O'Connor, 2010; Bartlett & O'Connor, 2007). Taking the person's experience as central heightens the importance of understanding people's biographical complexities and its inter- and intra-personal meanings (for example, in this case, how individuals have constructed their identities prior to, during, and beyond the onset of dementia). Thus, it should not be surprising that oral history be considered as a methodological tool for exploring personal narratives and the consequent impact these have upon the sense of the person themselves, for example in terms of socialisation, identity formation, public engagement and collective memory-making. Yet attempts to do so have been scarce to date. This may be because, subconsciously or otherwise, scholars have presumed that the cognitive difficulties associated with dementia (e.g. memory loss and accuracy of recall), have rendered the approach unreliable and problematic with regards to empirical veracity. Such issues cut to the heart of intellectual rigour and can be difficult to resolve both practically and philosophically.

## **Sport and Dementia**

In this article we report on a unique project which utilised oral history methodology undertaken with four people with dementia to explore their sense of identity within the context of their sports and physical activity histories. An oral history approach afforded opportunities to understand the values individuals' ascribed to sport/physical activities within their contemporary identities and daily lives. Findings and conclusions were made possible that would have been inaccessible using alternative methodological approaches, such as documentary analysis, because the project explored first-hand accounts (Walmsley & Atkinson, 2005). The paper presents the underpinning research and summarises the use of oral history methodology. The challenges encountered, and learning points identified

from the data are then discussed. Ultimately, the paper argues that when participant and contextual sensitivities and sensibilities are adopted (here with a specialist cohort), oral history may work as an effective method of enabling reflection upon times past for a group of people ignored until now, with unique narratives to relate. In this way oral history can enable historical experiences to be brought into the light, enjoyed, scrutinised and understood.

The intersection of sport and dementia within research is a fairly new phenomenon. Indeed the stereotype of dementia means that having dementia is associated with disengagement rather than activity. There are, however, a number of benefits that remaining active and engaged have in people's lives. Within contexts where sports and dementia meet there have been two areas of focus. The first has been the involvement of people with dementia (and/ or people at risk of developing dementia) in physical activity as a way of mitigating actual or possible symptoms to slow the course of the disease. There is some evidence that what is beneficial in terms of cardiovascular health can have value for brain health (ADI, 2014). The second area centres around sports nostalgia and reminiscence initiatives that seek to use memory about sporting past-times and events for the therapeutic benefit of participants. There may be some usefulness also in reminiscence utilising sport, because it can be framed in terms of an enjoyable and sociable experience, but its rigorous therapeutic worth remains unproven (Clarke, 2015; Woods *et al.*, 2018). Nonetheless, as evidenced in both the limited literature of sport, dementia and reminiscence 'therapy', intersectional initiatives between sport/physical activity and dementia comprise substantive historical thinking and doing. Moreover, it is evident that acts of archival assessment, historical recovery and authorship and narrative craftsmanship are at play. Yet, irrespective of history's heuristic and holistic potential, understandings of how historical methods (here the oral, but more broadly as well) might affect how communities are researched by scholars and represented remain limited. In light of these uncertainties the research underpinning this article was motivated by a desire to learn more about how the sporting context of people's lives might contribute to enabling people with dementia to live well. Identity was the focus because having a robust sense of identity contributes to personal welfare and adjustment to the vicissitudes that dementia brings (Bunn *et al*, 2012; Caddell & Clare, 2011). The study embraced this within a specific leisure context by exploring, 'How does

engagement with the activities of community-based leisure and fitness centres enable people living with dementia to maintain and develop their sense of identity?’

The oral history approach worked well in combination with the methods employed in the research. These were naturalistic and participatory, and frequently involved the researcher engaging with participants with dementia as they took part in sport and physical activity. Our article goes on to discuss these methods, detailing how they facilitated the gathering of oral history. This approach was in contrast to how qualitative dementia research has been conventionally undertaken. As understanding of the practice of research with people with dementia has grown orthodox methods have been criticised. For example, formalised interviews, conducted in traditional, ‘static’ ways hinder people with dementia from contributing their insights, particularly where those interviews lack sensitivity to the context of the person and topic (Lloyd *et al*, 2006). Instead, researchers have been encouraged to embrace the person-centred milieu within their discipline, and put the participants’ needs and wishes foremost within the design and delivery of their methods (Moore & Hollett, 2003; Phillipson & Hammond, 2018). As we will see these were motivations that helped shape our own methods, and with this in mind, the article turns to a short discussion of our methodology.

## **Methodology**

Phenomenology provided the underpinning approach for the research. This was particularly because of its emphasis upon the interpretation of human experience, its ability to enable exploration of the role and meaning of the physical environment/ place, and, its focus upon how a person might use their body to engage in activities as an expression of meaning (Lindelof *et al*, 2017; Kusenbach, 2003; van Manen, 1997). Phenomenology, applied to the sporting history context, offers value through encouraging the researcher to be open about their enquiries, as free as possible from preconceptions about what they might find, and to enable participant voices to come to the fore (Kirby, 2008).

The methodology ensured that the inquiry sought to understand the lived experience of dementia. Thus, the research participants with dementia, their stories and first-hand experiences of engaging with physical activity, were placed front and centre of the enquiry. Alongside this the environment, places and spaces where they now engaged in sport and

physical activity were included. Emphasis was given to interviews and observations which were based on understanding and using life histories to invoke conversation and evoke memories. Through this use of oral history the research methods collectively contributed to the recovery (and also forgetting) of memories. In turn this enabled the researcher to construct a shared and critical dialogue about the past and what it meant to participants' lives and abilities in the present. Taking these strands together the methodology was characterised by a keen interest in hearing the original voice of the research participants. Oral history offered a most appropriate means to these ends, not least because it advocates interaction with participants whose reflections upon their past are offered first hand (Perks & Thomson, 2015, p.3), and can contribute to the acceptance of change through the life course, and the nuances inherent in the maintenance of self-identity (Thompson, 2017; Bozzoli, 2015).

However, prioritising the direct accounts of people with dementia presented potential issues. In particular, would the cognitive difficulties characteristic in dementia (specifically memory loss, issues with cognitive sequencing, and impaired verbal communication), prevent the capture of 'authentic' accounts and data (Bennett, 2018)? Thus, in pursuance of a person-centred and social citizenship focus the researcher conducted an extensive consultation with people with dementia and family carers, with the aim of co-constructing the focus of enquiry for the research and the mechanism through which it would be achieved (Mayrhofer *et al.*, 2018; Mann & Hung, 2018). Findings from this and relevant literature (Smith & Sparkes, 2016; Silverman, 2017) advocated participatory methods, with an ethnographic focus, should be employed to guide the data collection, blended alongside the more conventional interview methods. They also stressed the significance of building rapport with participants with dementia (Genoe & Dupuis, 2014). Thus a methodological goal was to build trust between researcher and respondents, and encourage time during research episodes to be afforded to enable participants to contribute as fully as possible.

Based upon these considerations interviews and observations were undertaken with four people with dementia. These participants were recruited because they were actively engaged in physical activity at their local leisure centres or the fitness gym. The research took place over a period of ten months between the winter of 2017 and autumn 2018. A maximum of four interviews were undertaken, at intervals of approximately six to eight

weeks, with each participant. At least one of the interviews with each participant was conducted in the ‘go-along’ format, whereby the researcher facilitated the interview alongside the participant whilst they were engaged in physical activity at the centre/ fitness gym (Kusenbach, 2003). This involved the researcher participating in a range of sports and/or physical activities with each of the participants with dementia. These included badminton, table-tennis, darts, chair-based exercise and gym classes (both in group settings), and individual weights sessions alongside an instructor. Every interview had a qualitative and naturalistic focus striving to investigate the lived experience of each participant, with the aim of enhancing the chance to gather personal insight (Sarantakos, 2013, p.280). The researcher was also able to observe participants by being alongside them in the sporting context. Additionally, interviews were undertaken with other people relevant to participants’ engagement within the centre - for example, family carers/ partners, and the sports practitioner/ employee who had most contact with each participant with dementia.

The discussion now turns to the presentation of short biographical vignettes to contextualise participants’ lives and provide the connections between sport, dementia and the complexities of oral history work. Each person is given a pseudonym.

## **Participant biographies**

### Ivan

Ivan was sixty years old at the time of the research. He had been born and raised within a happy and settled family in a city in the West Midlands of England, where he lived until he moved to study at University in his early twenties. Subsequently he qualified as a dentist, a profession within which he worked – offering dental care to the same urban community close to where he grew up throughout his career – until he retired on grounds of ill health (caused by dementia) in his mid-fifties. Participating in and spectating at sporting events had played a significant role in Ivan’s life from childhood. Initially this involved being part of school football teams, progressing to University level participation in football, rugby and cricket teams, the latter providing opportunity to engage with a county level trial with his local county cricket club whilst at University. He was unsuccessful but continued playing sport, in particular five-a-side football, into his late fifties. Sporting participation generally

had social motivations, alongside the desire to 'keep fit' (Allender *et al.*, 2006). Ivan supported the same professional football club all his life, 'Denham United'. Attendance was rooted in family tradition and ritual, he was taken to watch this local team by uncles when a child, and he continued as a season ticket holder throughout his life - initially with family members but increasingly with friends from his peer group, several of whom were lifelong companions. After his first marriage ended in divorce he married Jemima when in his forties. The couple had a shared interest in sports and physical activity, and this included running after work and attendance at the gym. During these years Ivan attended football matches with his daughter from his first marriage, she having become a similarly loyal supporter of Denham. Diagnosing Ivan's dementia was difficult, partly because concerns arose when he was relatively young, fifty-seven, and because his symptoms were rare and unusual.

Diagnosed as 'cortical basal degeneration' the illness meant that Ivan had difficulty with speech, and with his movement and dexterity. Ivan remained able to remember events with relative clarity, but struggled to articulate them in detail because of problems with vocal communication. Following diagnosis he continued to engage in physical activity, often alongside his partner, at the local community fitness centre he had attended for over ten years, and at a local professional rugby club which had started to offer weekly exercise and social activities for people with dementia. Ivan passed away within a few months of his sixtieth birthday for reasons linked to his dementia. He had continued to play sport and attend matches of 'Denham United' until the final weeks of his life.

### Paul

Paul was in his late seventies at the time of the research. He had lived most of his adult life in a market town within a rural part of south-west England. Paul was employed all his working life in factory work, then as a technician with a quarry company and latterly as an assistant to a financial advisor. During early adulthood he undertook three years of national service in the Royal Air Force, serving abroad for part of this time. Paul was closely involved in sport local to his place of residence throughout his life. He played regularly for his town's amateur football and cricket teams, and in later years held administrative responsibility within the cricket club. He was a supporter of the professional football team closest to his home and frequently travelled to watch them, usually with a consistent group of male friends, until his late fifties. Indeed there were links from the study's findings between the

sporting contexts within which Paul engaged and how he constructed his masculinity (Dana, Kivel & Johnson, 2009). Subsequently he spent part of his leisure time watching his local county cricket team on a regular basis. Paul took part in marathons and half-marathons until he was in his mid-fifties. The desire to stay physically fit and enjoyment of playing motivated Paul's engagement in sport in the years before his diagnosis. Paul has been married to Connie for over fifty years. The couple have one adult daughter, who lives in the United States of America. Increasing difficulty with memory led to a diagnosis of Alzheimer's Disease when Paul was in his early seventies. His symptoms have included short-term memory loss, and anxiety (possibly as a result). Paul has trouble remembering recent events, but retains a reasonable ability to recall things that happened thirty or more years ago. Paul engages together with Connie on a weekly basis at his local leisure centre, in 'Arby', alongside other people with dementia in a group/ club environment that is facilitated on behalf of people with the illness. Paul enjoyed and valued these occasions because the activities on offer, in particular the table-tennis, provided him opportunity to continue to demonstrate a high level and skill and dexterity reminiscent of his younger adult life as a keen amateur sports player. The dementia, in particular its impact upon his memory, has meant that in other aspects of his life, for example socialising in company, he is no-longer able to exercise such competency.

#### Leonard

Leonard is in his mid-sixties and has lived in or close to a large city in the south-west of England all of his life. His early years were difficult primarily due to the behaviour of his father, which was neglectful and sometimes violent. Leonard did not enjoy school and held a negative attitude toward the sport on offer during his years in education. This was despite being a good middle distance runner and strong swimmer. Later, in adulthood, Leonard enjoyed riding his bicycle recreationally and motor-cycling. The latter activity was accomplished alongside a peer/friendship group. Motorcycling is the only sporting activity Leonard has ever been interested in as a spectator, for example combining his participation with attending organised professional events. Married to Caroline, and with two adult children, Leonard has been employed throughout his adult life. He worked as a French polisher for most of this time. When his employer closed, due to there no longer being demand for such skills, Leonard worked as a school caretaker until he had to retire because

of ill health (caused by dementia) when he was sixty years old. Leonard has posterior cortical atrophy, the symptoms of which result in a compromised visual ability and spatial judgement, as well as having impact upon his short-term memory. Leonard and Caroline have been attending the same group/ club at the leisure centre in Arby as Paul and Connie for over two years. However, Leonard and Caroline extend participation across the week, beyond the activities of the group, to include games of badminton on other days, and attendance at social events there too, and this is shaping his sense of identity post diagnosis (Perras, *et al.*, 2015). Motivated both by his desire to push-back against the impact dementia was having, and as an outlet for frustration linked to his childhood experiences, Leonard prefers physical activity of a more vigorous sort than many of his colleagues within the group, seeking opportunity for games of badminton and swimming sessions that are bodily demanding.

#### Jacqui

Jacqui is in her early sixties and lives alone in a village in the West Midlands. At school she was a highly competent athlete – a runner, good enough for selection for competition at county level. Jacqui was discouraged from continuing to participate by her parents, her father in particular, who required her to prioritise paid employment as soon as she was old enough to get a job. In her thirties and forties Jacqui took up running again, primarily for pleasure. Physical activity has always been important to her, for example helping to determine her choice of employment – her last job being with the post office. Jacqui had a difficult relationship with her husband, which contributed to a divorce and estrangement from her children and grand-children approximately four years ago. At the same time she was experiencing difficulties with her health which ultimately led to her retirement from employment. After a short period of uncertainty she was diagnosed with dementia with Lewy bodies. This has meant she experiences difficulty with posture and physical dexterity, alongside compromised ability to read and write. Whilst her long-term memory remains relatively strong, more challenging for Jacqui is swiftly sorting and making sense of recent events. Jacqui goes to her local leisure centre on at least three days every week, taking part in organised fitness classes, but also on occasions attending the gym and swimming pool on her own. Participation in physical activity offers opportunity for Jacqui to test her own competency in daily life, choosing to do this within a public leisure space even despite

popular culture tending to deny female role models to support this (Brabazon, 2006). This appeared to add to the challenge Jacqui perceived, as she strove to push back against the difficulties dementia imposed upon her, and was thus attractive to her.

## **Recognising the challenges of utilising oral history methodology, and approaches and techniques that release its potential**

### **The Cognitive Challenges of Dementia**

Participant data acquired in the study demonstrated it is possible to utilise recall of sporting history as a methodological tool for exploring personal narratives, and the consequent impact these have upon the sense of the person with dementia themselves. For example, personal reflections illustrating that, in spite of the sense of loss dementia brings, the desire to continue to fulfil an active role in one's life, inclusive of skills and interests, remains. With this situation in mind the article moves on to identify the challenges dementia presented to the oral history methodology, before progressing to highlight the manner these were overcome and some of the novel historical insights gathered as a result.

The research discovered the challenges inherent in the process of gathering oral history were linked to the symptoms of the particular dementia related illness pertaining to the research participant. Thus, for Paul, Alzheimer's Disease meant he had difficulty recalling past events confidently and clearly. Additionally, he no longer trusted himself to articulate what he wanted to say, because of the dementia he had lost confidence in being able to express his opinion. Leonard too found the posterior cortical atrophy caused some difficulty with memory. Jacqui retained relevant memories and could talk about them in detail. However, they often had become hidden beneath the more pressing concerns her dementia caused – typically relating to her day to day functioning (for example, feeling well enough to leave her flat to shop for essentials). Ivan's difficulty was not so much the recall of memory, the cortical basal degeneration meant that he had extreme difficulty verbally articulating these. The researcher was obliged to reflect upon these challenges and employ a range of approaches and techniques to access the rich narratives each participant held. The following sections detail the approaches he took, and how each afforded the participants with dementia opportunity to contribute their oral history. They are not mutually exclusive and

overlap. Taken together they indicate how the oral history process can contribute to the exploration of personal narratives of people with dementia in the context of their sporting history.

### **Building rapport with participants**

Building rapport with research participants with dementia was highlighted as important in the study's consultation with people with dementia and their families, and its significance is recognised by scholars of research practices from both the dementia and oral history contexts (Digby *et al* 2016; Cridland, 2016; Yow, 2015). Thus from the outset of the research a priority was to build and sustain relationships with research participants characterised by trust and rapport. Achieving this meant insight on personal historical experience was gathered, which was illuminating and instructive. For example, Jacqui was able to articulate a wealth of information about her sporting history and its relevance to her:

“...when I was young I was picked for the town sports, which I wasn’t allowed to do by my Dad. So I was always good at running. I did the normal things in school, tennis, hockey whatever... I had to go through a lot of heats through the school sports, and then inter-school, until I got picked to be in a Warkham team, which would have gone national.”

Later in the interview Jacqui added more detail, evocative of her earlier adult life:

“...a lady over the road...used to say to everybody, “who’s that woman that runs everywhere?” (Jacqui laughs) “Whoever is she?” And, even when I was dressed normally I would always go at a pace... everything would be at a pace. And cycling...It was available. It was freedom. It was just freedom to escape from restriction. Freedom to escape from life, at whatever age, for whatever reason....The bike just got me further faster...I just found that was there and...for once I could say I could do something without somebody saying ‘you can’t’.”

Jacqui was able discuss what she enjoyed about engaging in physical activity. She highlighted the sense of freedom it offered - freedom in a physical but also in a psychological sense. She was away from the negative influence of others, and to an extent from her own negative perception of herself. The researcher achieved this engagement by taking the approach that best suited to the needs of the participant, a well-established

component of oral history (Perks & Thomson, 2015, p.4). In Jacqui's case this was about listening closely and attentively, and offering her time to relate what she wanted to say. Preamble also helped, for example, conversation about matters of pressing concern to Jacqui, such as her transport difficulties in attending the leisure centre regularly. Once she felt calm and settled Jacqui was able to offer rich reflection upon her motivation for engagement in physical activity, apparently unhindered by the symptoms of dementia.

Building rapport by attuning himself to the needs and priorities of individual research participants was one way in which the researcher sought to maximise the effectiveness of the oral history approach. However, this required research methods to underpin empathy, and thus fully utilise the value of oral history techniques. The article now turns to a discussion of two of such methods, go-along interviews, and use of photographs from participants' pasts, exploring how they facilitated exploration of oral history with people with dementia.

### **The Go-Along Interview Method; playing sport together**

The 'go-along' technique, where the researcher engaged alongside the participant with dementia in physical activity/ sport, assisted understanding of participants' sporting histories by providing opportunity to build rapport to facilitate conversation, and to tailor the interview to individual physical and cognitive abilities (Digby *et al.*, 2016). This enabled participants to recall events in conversation with clarity and put them at ease allowing a freer flow of information. The value of the technique in building rapport is demonstrated by the following passages taken from two interviews with Leonard, presented in tabular format.

| <b>Example 1. Interview at Leonard's home</b>  | <b>Example 2. Interview immediately badminton game concluded</b>  |
|--|---|
| <b>Leonard:</b> When I was at school I never played any sport...I had no interest in football anyway, and the cross country running was part of the P.E., so you had to do it... | <b>Researcher:</b> ...before diagnosis you...didn't do much sport, so was keeping fit still important to you then?<br><b>Leonard:</b> Oh yeah, yes it was.<br><b>Researcher:</b> How did you keep fit then if you didn't play much sport? |

|   |   |
|---|---|
| <b>Researcher:</b> ...after school did you ever play any type of sport? | <b>Leonard:</b> Well through work mainly.   |
| <b>Leonard:</b> No.   | <b>Researcher:</b> Physical work?   |
| <b>Researcher:</b> Nothing.   | <b>Leonard:</b> That's right yeah...  |
| <b>Leonard:</b> No.   | <b>Researcher:</b> ...what are the reasons...you like about feeling energised and taking exercise? What is it that you like about it? |
| <b>Researcher:</b> Nothing.   | <b>Leonard:</b> Well just being physically fit, being able to do what I want to be able to do...                                      |

The first occasion, convened using a conventional interview style at Leonard's home, is characterised by a lack of information exchange and stilted responses. The second dialogue, a month later, comes immediately at the end of an hour-long game of badminton Leonard played with the researcher. It is more expressive in terms of his personal narrative about his sporting past and its influence on his life as he sees it. The clarity of Leonard's recollections were enhanced because the second interview took place on court immediately at the conclusion of the game. Part of the effect being that recent memory brought the interview to life and encouraged Leonard to engage enthusiastically.

Researcher: ...we had a great game.

Leonard: We did have a great game, yeah.

Researcher: It was a lovely game wasn't it.

Leonard: You coming back?

Researcher: I am. I am coming back. (Leonard is laughing).

This dialogue is noteworthy because the reflections are upon the enjoyment of the game of badminton recently played. This was mutual enjoyment and helped strengthen the social bond between Leonard and the researcher. This was especially valuable in light of what Leonard reflected about how his memory was not as strong as this under normal circumstances, and he lacked confidence in it. For example,

"Yeah, cos I'm doing it. I remember what I did..." .

The researcher used an identical approach in an interview three months later. Leonard was able to articulate how he felt about engaging in sport and physical activity that day, just after their game of badminton concluded.

“It takes your breath away. It’s brilliant.”

The change from the stilted and minimalist response in the interview at home six months earlier is clear. Use of the go-along technique had enabled rapport to be built between the researcher and Leonard. It had evoked clear and apparently genuine reflections from him on his feelings about his current engagement in sport. Additionally, the longitudinal approach to the research allowed for substantive conversations to be developed, and memories to be opened up to far greater scrutiny and reflection than they might ordinarily be in a discrete 1-1 session (Hughes *et al.*, 2019).

The go-along method provided similar positive outcomes with Paul. For example, during a game of table-tennis at his local leisure centre, he was laughing with the researcher as he headed the table tennis ball and said,

“See, just like playing football!”

When reminded of this at the end of the game he said,

“I was a centre half you know. My job was to save the team...You’re on it most of the time”

This comment by Paul, whilst short, communicated much about his identity and what engaging in physical activity meant for his sense of self, then and now. The difficulties he had with long-term memory and the anxiety this caused him meant Paul tended to say little. The go-along context, however, had enabled him to demonstrate some of the technique he used when playing football years ago, and afforded opportunity for him to reflect on that with clarity and insight. The following passage, part of an interview held as a game of table-tennis with the researcher concluded, demonstrates again the value of the approach. Paul is describing how he approached opening the batting in a game of cricket.

Researcher: Did you ever feel under pressure..?

Paul: No, I didn't feel any pressure...you just hope that you're gonna...and after about five or ten minutes you're in and you know you can go on for...But you know, you could be out first or second ball, you know, it could happen.

Researcher ...if you got set how did that feel?

Paul: Felt good...Yeah...It did feel good....I used to enjoy my sport.

Researcher: Can you tell us a bit about what was enjoyable?

Paul: Well, scoring a lot of runs was! (Paul laughs heartily)...Yeah, I used to like it...I liked to play. You know you win some and you lose some, but you know, you always try your best.

This shows how, through linking to a conversation soon after Paul had engaged in sport, it was possible to gather insights and reflections that contained a high level of detail and emotional memory about his experience. The activity of playing sport aided recall. The complexity of reflection was much higher than Paul would offer otherwise. As noted above, the insecurity Paul felt in relation to his memory discouraged him from saying much at all about anything anymore – certainly to relative strangers such as the researcher. Finding such ways to overcome the inherent fragility of memory, and associated lack of confidence, helps address a significant challenge found in both sports and dementia related research seeking participant narratives (Perks & Thomson, 2015; Hampson *et al.*, 2018).

### **Using Photographs**

There were other techniques the researcher employed to establish rapport and encourage participants with dementia to articulate their sporting histories in depth. One was the use of photographs from their sporting past. For example, here with Paul studying a team photograph from the nineteen-fifties, and facilitating an account of his career as a defender with his local football team.

Researcher: That's you. Because you're tall really aren't you? I think you're always the tallest.

Paul: I am tall, I'm six foot one.

Despite having difficulties with his memory Paul can remember his height. As the interview progressed Paul continued to study photographs, and related more about how he would play football.

Researcher: So did you used to head that football?

Paul: Yeah, you're a defender...I used to play centre half, you do.

Researcher: ...so what was your job in the team?

Paul: Saving the team.

Researcher: Did you ever want to play in other positions?

Paul: I played in centre half....

This passage highlights how Paul retained a clear sense of his role in his football team and his job in that position. This has resonance with his earlier descriptions of how he opened the batting. Later, other photographs were on view, ranging from Paul's footballing career to photos from his more recent days as a long distance runner.

Researcher: How does looking at these make you feel?

Paul: Brings it all back to memory now.

Researcher: What sort of memories Paul?

Paul: ...You know I feel fit...Looking at these, probably that's what I was running for.

The use of the photographs helped Paul recall elements of his sporting past. The technique would sometimes take a while to be effective, highlighting again the importance of building rapport and putting the participant at ease. However, the images often elicited emotional memories that assisted Paul link back to his past experiences (Hughes *et al*, 2019).

The researcher used photographs with a different participant, Ivan, in another way, utilising a 'bridge building' technique whereby he shared information personal to his life to draw out accounts of Ivan's history of sports participation. Drawing on their shared history as life-long supporters of Denham United, the researcher showed Ivan photographs of a family day out from a match both had recently attended, separately and unknown to each other, before they met. This extract from his research diary explains what happened,

"Ivan took his time and reflected that the things he remembered most were the good atmosphere, and meeting acquaintances he had not seen for years. When I mentioned Denham United his expression changed into a large grin... Ivan said that he enjoyed home matches more because he met friends there. He smiled when he said this. I related that from what I had heard Ivan's identity on the football pitch was in the style of Liam Main or Martin Dixon, two physical players. This made Ivan smile broadly and he nodded."

This shows how by bridge building, here with photographs, the researcher was able to strengthen the feeling of rapport between himself and Ivan. The technique garnered information relevant to Ivan's personal history of sporting engagement. Whilst it is important to craft individual participant narratives well in oral history, it is often difficult to do (Sugiman, 2009). The technique enabled this, with Ivan able to recount how camaraderie had played a valuable part in his sporting history, and how his own football playing style was physical in nature – akin to those players mentioned. His smiles and facial expressions often aiding understanding of this. Indeed, non-verbal forms of communication proved to be so significant in the context of this discussion that the topic requires particular consideration.

### **Appreciating para-verbal and non-verbal cues in the oral history process**

Recognition of what is offered verbally by participants must be complemented by an appreciation of communication made using other senses. In particular, this relates to the facial expressions of participants, their body language, and the tone of their voices. Any qualitative interview must be supported and complemented by the use of naturalistic data to have integrity (Silverman, 2017). Thus, the photographs were useful because symptoms of the cortical basal degeneration reduced Ivan's ability to speak, so pauses when looking at them offered him time to gather and articulate what he wanted to say (Kertesz & McMonagle, 2009). This was supported by 'active listening' by the researcher, giving Ivan as much time as he wanted and needed to offer his reply. All the while taking note of Ivan's para and non-verbal communication to determine his readiness to move on, and also to divine clues to the meaning he was offering (Yow, 2015). Oral historians are encouraged to note the tone, volume and rhythm of speech for implicit meaning (Jessee, 2015), and such an empathetic approach is an important part of good practice when working with people with dementia (Mason & Wilkinson, 2002, pp192-201; Scottish Working Party on Dementia, 2013).

We have seen how the use of go-along interviews assisted in building rapport with participants, and enabled them to offer reflections in detail. The approach also had the advantage of eliciting information that was embodied and multi-sensorial (Smith & Sparkes, 2016). This was because the go-along interviews were situated within the environment, including its sights, sounds and smells, that related to the activity which was the subject of enquiry – here sporting past-times (Hung *et al.*, 2017). For example, here Ivan reflects upon games of five-a-side football with his friends, just after he has completed an exercise session at his local community fitness centre.

Researcher: Was it good fun?

Ivan: It was.

Researcher: ...being with the others and...

Ivan: Yeah (very long pause)

The opportunity to return to a space similar to those where he would have engaged in sporting activity in the past acted to evoke memories that were emotionally powerful. Ivan's ability to verbally articulate what he wanted to say was impeded by dementia. Active listening was important, giving Ivan time to reflect. Here it was that final silence which was as descriptive as his words, accompanied by his sudden broad smile, as he contemplated those games from his past and what they meant to him. As the interview continued Ivan turned to his memories and feelings about how he played the game of football.

Ivan: Yeah. Well, I tell you what I've got! (He is smiling and pointing to his knee).

Jemima: Oh! He broke his knee, that's what he's trying to tell you. (Both Ivan and Jemima are laughing)

This demonstrates the power of para-verbal and non-verbal cues to foster meaning and insight, here illustrating Ivan's feelings and recollections about how he approached playing football as a young man. In the absence of speech Ivan points to his knee and smiles and laughs. Jemima, who knows him well, helps the researcher understand the significance of this – i.e. he always played hard and competitively, and he remembers this. This is an example of the importance of non-verbal communication to understanding Ivan's recollections on his sporting history and the value he accords to them.

A similar example involves Paul, as a go-along interview was concluding after a game of table-tennis with the researcher.

Researcher: You are a good player Paul.

Paul: You never lose it! (Paul smiled broadly)

This comment is short but communicates much about Paul's identity and what engaging in physical activity means for his sense of self, in past times and present. Paul's facial expression, he was grinning whole-heartedly, adds power to the interpretation.

Participant observation played an important role in enabling the lead researcher to garner meaning from what participants communicated in ways not involving spoken dialogue. The researcher was part of the setting where the observed activities took place (Thomas, 2013), but it was easier for him than when conducting go-along interviews, because there was no requirement to engage overtly, particularly verbally, in the research episode. Instead the way was left clear, in a manner congruent with the study's phenomenological underpinnings, to explore how participants used their body to express and negotiate meaning (van Manen, 1997). The manner in which they engaged with the leisure and fitness centres activities' enhanced the researcher's ability to understand what these experiences meant to them in the context of memories of their sporting past (Bond & Corner, 2001; Kissow, 2015). For example, the following is taken from the researcher's diary, following a participant observation with Paul as he played table-tennis.

"...Paul was absolutely focused on playing...He smiled a great deal. He enjoyed it. Paul gave his all physically during the games...It means a lot to him..."

This observation allowed the researcher to understand more about how Paul felt about participating in sport, , in ways he might find difficult to articulate through speech. It was a timely technique in Paul's situation because an entry in the research diary had noted during an interview:

"Paul become nervous as he felt his memory was being tested and he feared the consequences himself..."

Impaired memory not only presents the challenge of reduced ability to recall events. Self-awareness on the part of the participant also has consequences for their confidence

(Gaugler *et al*, 2011). Paul felt trepidation about his ability to recall details from his past, which he perceived as transparent in the context of a verbal encounter. Indeed interviewees may attempt to ‘read’ the interviewers expressions, their reaction influencing how they in turn respond and contribute (Yow, 2015). Instead participant observation afforded Paul opportunity to participate in the research in a manner that was expressive, but without feeling pressurised. Once more, this links to the study’s phenomenological underpinning, as it relates to the use of one’s body to express and negotiate meaning (van Manen, 1997).

Thus far we have seen how building rapport with participants, and aligning research methods to facilitate a sense of empathy were key components in the success of the oral history approach. There were moments, however, when more was required. Most prominent was the contribution made by the family carer of the research participant with dementia. It is to a discussion of this that the article now turns.

### **Interviews with, and help provided by, family carers**

The research took account not only of the reflections of the person themselves but also from those close to them, particularly their partner/ carer. Their recollections offering valuable context and insight to accompany that of the participant with dementia (Murphy *et al.*, 2015). For example, Jemima, wife of Ivan, recounted,

“It’s been a major...major thing in our life sport...I don’t know what people do, who don’t do sport. I can’t imagine what they do (she laughs)”.

Connie, wife of Paul, related,

“I’m a sporting widow (laughing). Or I was...you knew what the deal was...It’s always been part of his life...”

However, a risk was that nostalgic recollection could temper the veracity of accounts (Hughes *et al.*, 2019). Understandably people with dementia and their family carers might feel inclined to revive times where they felt healthier and more secure. Teasing out what this signalled for understanding sporting heritage was important. For instance, in the case of Paul and Connie the weaving of nostalgia and reality ran deep through their accounts. For example, Connie related,

“...for the cricket...in the summer we wander up there...we don’t know anyone now...it’s not like the old days.”

Although, invariably, reflection can be influenced by memories that are less positive too. Here Leonard’s wife, Caroline, reflects upon her husband’s historical motivation to engage in physical activity.

“...I think you always felt like you got picked on because you were little. And you were weedy. And he (Leonard’s father) used to make comments about that...You always wanted to be as big as your mates didn’t you really. And you were always skinny...”

The revisioning of personal histories by individuals is a feature of oral history practice that requires critical attention by the researcher (Sangster, 2015). In our study the researcher endeavoured to do so. However, simultaneously he recognised and accepted the risk nostalgic recollections might have posed to the study - not least because memory offers a link between past and present in ways that can help understand changing personal identity (Perks & Thomson, 2015). The subsequent conclusion (below) offers further consideration upon this and its consequences.

As well as providing their own recollections, family carers can enhance the memory making process through their contribution to data gathering alongside the participant with dementia. For example, Jemima worked with Ivan in the manner the couple had agreed, as ‘a team’, i.e. to help her husband to contribute matters relevant to his sporting history. This had been anticipated by the couple, because of Ivan’s difficulties with speech. Here is one example, which enabled a vivid account of Ivan’s county cricket trial to be re-told. He held clear recollections of the event, one which went wrong, and was a significant moment in his life. However, without Jemima’s contribution these would have remained buried.

Jemima: And he loved playing cricket as well, you went for a trial didn’t you? One of the county ones.

Ivan: Yeah.

Jemima: Tell Chris about that...

Ivan: Left turn or...

Jemima: Left arm spin.

Ivan: Left arm spin...and er I was playing...I went up to... or played the ones, the next, erm, then we went, erm...I think, had the erm, when they do erm, they might say, four or five on the, erm, I managed, I sort of ...

Jemima: Do you want me to try?

Ivan: Yeah you can if you like, yeah.

Jemima: Well only if you want me to...

Ivan: Well, just, I was near to getting through, the only problem was I'd messed up my, which was erm, split, and so I went on, because I wanted to, some more, rather than just the star.

Jemima: What he wanted to do, he was a left arm spinner and you'd had a go at doing a slightly different spin...And when he went for the trial for the County or one of the clubs he'd changed his spin hadn't you?

Ivan: Yeah, and I couldn't....

Jemima: So who knows if...

Ivan: When I used to go down the town, not the town, anyway this was kept and...(long pause)...er, I just thought...

Jemima: Which club was it you went for? I don't know, so I'm not trying to test you. I can't remember what you said, was it the County..?

Ivan: County, yeah.

It is only someone who knows the participant well and whom is trusted who could intercede in this way. The support Jemima provides enables insight to be given by Ivan in a manner that overcomes the impairment his dementia presents. Because Jemima knows Ivan so well, she knows when and how to intervene to support him offer his unique account.

A similar example is provided by Connie, here assisting her husband Paul recall times spent playing cricket. She steps in with a first-hand insight, about what their young daughter used

to say, which enables Paul to reflect on the occasion and communicate how he felt about it – this time via his facial expression.

Researcher: I wonder if you scored a big score that day?

Paul: I can't remember.

Connie: She used to say...good luck Dad score plenty of runs...

(Paul laughs and smiles)

Researcher: Oh that brings a smile to your face...

Paul: Yeah.

### **How might oral history work as an effective method of enabling reflection upon the experience of living with illness?**

Recent scholarship by Bartlett & Brannelly, 2019, has brought a story-telling approach to research exploring the lived experience of dementia. Basing their technique on the work of Arthur Frank, medical sociologist, they argue that through telling their stories people with dementia subvert stereotypes, typically the stigmatising narrative that they are incapable and incompetent. Bartlett and Brannelly identify Frank's concept of 'illness narratives' as significant, arguing that the nature and scope of the 'illness narrative' told about a person will have a corresponding influence upon their sense of themselves. This is timely in the context of our discussion, because the story-telling method has similarities with the oral history approach, and because this contemporary research also focuses upon people with dementia. Lessons may be drawn by historians as a result. For example, as people tell stories about themselves and their lives they will offer expressions about their own sense of consciousness and identity that extend beyond detail relating to that occasion (Bozzoli, 2015). For example, in our study, the nature of 'freedom' as related by Jacqui's account of what running and cycling meant to her.

Additionally, when oral history is used to ascertain the experiences and perspectives of people with cognitive disability they bring a unique perspective through which conventional understandings can be challenged (Walmsley & Atkinson, 2005). This relates, in particular, to the ability of people with dementia to contribute special insight into feelings attached to

sporting endeavours, and their meaning. This forms part of the conclusion to the article to which we now turn.

## Conclusion

We have explored whether oral history works as an effective method of enabling reflection upon sporting pasts and through this upon the experience of living with illness. The accounts presented here suggest that people with dementia have stories to tell, and that these accounts hold value. It is further suggested that they offer insights others are unable to offer, and/ or have neglected to relate. In particular the value of emotional recall that accompanies memory of sporting events and contexts. An illustrative example is the risk of nostalgia obscuring the objective reality of participants' accounts of their sporting histories (Perks & Thomson, 2015). As we have seen this might particularly pertain to people with dementia and those close to them, perhaps holding a nostalgia for an irretrievable past characterised by feelings of physical health and well-being. However, nostalgia is linked to retrospective feelings of emotion, and much that is valuable about sporting endeavour comes from the good feelings it evokes. This is of relevance because oral history emphasises the construction of meaning (Portelli, 2009). If the risks attached to the influence of nostalgia on memory are explicitly recognised by researchers then emotional recall should play a role in understanding sporting histories. In relation to the present discussion we know that for people with dementia emotional memory remains strong (Guzmán-Vélez *et al.*, 2016). To exclude nostalgic recollection could inadvertently deny them a core and legitimate part of their sporting story, therefore. The intimate nature and interactivity of the research encounters within this study potentially enabled investigation of more than fact. Instead and in addition – aspects of consciousness and social identity were addressed (Bozzoli, 2015). Where it is seems to a researcher that a person with dementia's emotional recollections are strong, either through what they say, or how they express it (Jessee, 2015), they might be better placed than others, encumbered by full cognitive health, to communicate what the feelings attached to sporting endeavours genuinely mean (Bartlett, 2016; Bartlett & O'Connor, 2010; Bartlett & O'Connor, 2007). Indeed, recollections tempered by nostalgia might be the manner in which experiences are recovered, and inform how oral history approaches are evolved (Hughes *et al.*, 2019) - in particular as they relate to groups of people hitherto marginalised.

Further, the building of rapport is important to enabling effective oral history, not simply because it is good practice with research participants with dementia (although this is vitally important), but also because of the fallibility of memory. We accept a degree of this as historians, we still treat oral accounts with a degree of veracity (Oliver, 2017; Menon, 2017). Yet, the research reported on here reminds us that such authenticity remains fragile and we may need deeper and more long term relationships with participants in order to establish credibility in/of the data.

This discussion has also highlighted that good oral history must take into account a variety of senses and affective behaviours of participants. It must acknowledge also context, specifically, time and space factors – such as the capacity of participants for historical thinking, their independent ability to recall with or without others, and the influence of environmental cues such as photographs, smells and sounds. Thus, we are arguing for an oral history approach beyond merely the oral. This is how it should be. After all the ambition to understand history in its fullest sense is surely the goal to which we must aspire? The fact that people with dementia and those who love them have led us in this direction is powerful and exciting.

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