

## **Oral History, health and well-being, and everyday life with dementia**

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### **Description of Project**

Lack of disease modifying pharmacological interventions for dementia foreground the significance of research methods to support understanding of experiences of everyday life with the illness. Accordingly, this case study illustrates how oral history methodology might be mobilised for health and wellbeing and afford means to illuminate and advocate for individuals' voice within the health and social care sector. The case study draws data from a research project ('Because life's there...understanding the experience and identity of people living with dementia in the context of leisure and fitness centres', 2016-2019) conducted in the United Kingdom involving four people (three men and one woman, all living with different forms of dementia causing illness, e.g., Alzheimer's disease, vascular dementia etc.). The project aimed to understand experiences of regular engagement in physical activity, via their local leisure centre, with a specific emphasis on exploring ways involvement shaped participant identity. Cognisant of wider social and support networks, close family members and centre employees were included, if these individuals played roles in the experience of the person.

### **Methodology**

Focusing upon the interpretation of human experience, the research took a phenomenological approach that enabled exploration of the physical environment, and ways bodily engagement informed expressions of meaning. Synergising with naturalistic and participatory methods (e.g., go-along interviews, where the researcher interacted with participants during physical activity), an oral history approach was used to foster participant voice and dialogue, and elucidate personal narratives of time and space. The methodology entailed participants connecting memories of the past to highly individualised (re)creations of their lives and experiences in the present. Emphasis was given in interviews and observations on using life histories to evoke memories that invoked conversation. A minimum of four interviews took place, with at least one encompassing the go-along method. The methodological value is highlighted in this example, taken from a go-along interview with Paul, a man in his late seventies living with Alzheimer's Disease, during a game of table-tennis. Paul laughed with the researcher as he headed the table tennis ball and said, "see, just like playing football!" Reminded of this at the end of the game Paul said, "I was a centre half you know. My job was to save the team...you're on it most of the time". This encounter expressed much about his identity and what physical activity meant for Paul's sense of self, then and now. The challenges Paul experienced with long-term memory and the worry this caused him meant he was inclined to say little. The go-along context, and historically focused dialogue, however, enabled him to demonstrate techniques he used when playing football years ago, and afforded opportunity for reflection on that with clarity and insight.

To foster a positive and constructive dialogue, and enable individual's rich narratives to emerge, the oral history approach relied significantly on building rapport between researcher and participant. Beyond vital to the project's methodological rigour, rapport was paramount

for ensuring ethical integrity and credibility of the research by ensuring participants' comfort with data collection. Additionally, the use of participants' own photographs - illustrating earlier sporting experiences - furthered rapport and encouraged detailed articulation of sporting histories. Recollections of close family members contributed accompanying context and insight. Ivan, for example, was a man in his early sixties living with a rare form of dementia, corticobasal degeneration, which impeded his verbal articulation rather than memory. When describing early experiences of sport (here playing football in the street as a child) he reflected, "there's always people down there, whether it's you and your mates, or up or down from that you know...". His wife, Jemma, added, "you played with your cousins as well didn't you? They used to say that he didn't mind being an only one because there was always someone round".

Methodological challenges included the influence of nostalgia. However, an understanding of nostalgia offered ways of appreciating how links between the past and present influenced changing personal identity and emotions linked to sport participation. Excluding nostalgic recollection entirely therefore might have inadvertently denied individuals a core and legitimate part of their sporting story. Enabling a safe space for individuals to (re)create their own meanings and do so in ways that mattered to them was thus vital. Additional challenges were presented by the public nature of venues and participatory aspects of the research. For example, possible disclosure of personal information within a public venue (e.g., awareness others might gain that participants had dementia, if individuals wished this knowledge safeguarded), informing other attendees in the vicinity that research was occurring, and ensuring consent to the researcher's presence. Here, rapport building enabled the researcher to understand whether a person felt comfortable about others knowing their diagnosis and assisted in developing appropriate explanation about the research. Rapport also facilitated curtailment of a go-along interview if the risk of inadvertent disclosure of personal information became acute.

### **Methodological consequences and lessons**

An oral history approach offered means of exploring matters that were of personal importance to participants. Individuals were, specifically, able to reflect upon how involvement had changed over time and describe meanings and value they attached to their participation, identities, and everyday lives. Findings and conclusions were made possible that may have been inaccessible using alternative methodological approaches. For example, as described above, where Paul elucidated upon earlier times in his life with feelings of happiness and confidence. In such ways the project explored intersections between memory recollection, creation and first-hand experiences of participation in physical activity.

Utilising oral history, researchers could encourage participants to share aspects of their life story and consider how this mattered to their engagement and experience. Notwithstanding, there remains need to carefully consider the physical contexts/settings in which the research takes place, as well as the nature and content of the discussion (and how these might evolve over time with rapport). Accordingly, we advocate for longitudinal-style oral history approaches that transcend 'snapshots' of individual's experiences, and allows evolution of thinking, recollection and meaning to develop, be challenged, and remade over time. Thus, potentially, further crystallizing richer accounts of experience than might initially be retrieved.

Oral history helped bring to the fore the experiences of a group under-represented in sport history and wider health and social care historical literature. In taking the person's experience as central, and accounting for contextual sensitivities and sensibilities, the approach underscored the importance of individual's biographical complexities and its inter- and intra-personal meanings. For example, here, how individuals have constructed their identities prior to, during, and beyond the onset of dementia.

### **Suggested Pathways for Future Research**

Adopting historical understandings of the sort described in this case study matters because numbers of people living with dementia continues to increase as populations age and people are being diagnosed at earlier stages in the disease trajectory. Recognition of what is offered verbally by participants must be complemented by an appreciation of communication made using other senses. In particular, the facial expressions of participants, their body language, and tone of voice. An oral history approach beyond merely the oral may, thus, enable richer histories of identity, the body, and participation.

New projects are already building from this initial research. An online educational initiative provided by the Association for Dementia Studies (University of Worcester, UK), *Championing Physical Activity for People Affected by Dementia*, involves practitioners from social care, health and housing, sports and leisure enhancing practice by working in concert to engage with accounts from people living with dementia participating in physical activity. Yet, more is required. For example, the issue of what constitutes good facilitation of physical activity for people living with dementia remains unresolved. Oral history can shed light on this link and amplify individuals' voices who may benefit the most from enhanced provision, resourcing, and participation.