Physiotherapy 100 (2014) 169–175

Exploring experiences of physical activity among people with Alzheimer's disease and their spouse carers: a qualitative study

R. Malthouse [a,*], F. Fox [b]

[a] *Physiotherapy Department, Royal United Hospital, Bath, UK*
[b] *Department for Health, University of Bath, Bath, UK*

Abstract

Objectives To improve understanding about the barriers and facilitators to physical activity for people with Alzheimer's disease and their spouse carers, and to consider the development of activity interventions that would be acceptable, sustainable and feasible for both groups.
Design A qualitative approach, using semi-structured interviews, facilitated exploration of physical activity in a small group of people with Alzheimer's disease and their spouse carers.
Setting Participants were recruited from one memory clinic in South West England.
Participants Potential participants were identified by clinical psychologists at the memory clinic and were given information about participating in the research. Five people with Alzheimer's disease and their spouse carers were subsequently recruited for semi-structured interviews, which took place at the memory clinic. Interviews were audio-recorded and transcribed verbatim.
Main outcome measures Qualitative data were analysed using thematic analysis. Three major themes have been presented.
Results The findings illustrate the complex interplay between the overarching themes 'self', 'others' and 'couple' that affect physical activity for both people with Alzheimer's disease and their spouse carers, and which are linked to the progression of dementia.
Conclusions An individually tailored approach for couples, which values the role of the carer and accounts for the progressive and changing nature of dementia, should be a guiding principle for intervention design.

Keywords: Physical activity; Alzheimer's disease; Spouse carers; Qualitative

Introduction

Few published studies explore the personal experiences of physical activity in people with dementia. Some barriers to physical activity and adaptation strategies have been identified for this group [1]. Signs of dementia including memory impairment, aphasia, ataxia and behavioural changes may affect participation in physical exercise programmes, causing lower attendance and adherence rates, reduced exercise intensity and a higher risk of adverse events [2]. Spouse carers may support their partners to perform regular physical activities [1]. Conversely, caring for a person with dementia can have a negative impact on the physical and psychological health of the carer [3,4], and the extent to which carers can adhere to recommended activity guidelines for older people [5] may be compromised. The role of carers in facilitating activity for people with dementia and their own corresponding levels of physical activity therefore warrants further research. The term 'physical activity' is used here to include all forms of activity such as functional walking or cycling, work-related activity, active recreation, dancing, gardening, playing active games, and organised and competitive sport [5]. The term 'carer' is used to refer to the informal spouse carer of the participant with dementia.

Dementia is a common neurodegenerative disorder, estimated to affect one in six people over 80 years of age [6]. Symptoms include cognitive impairment, behavioural disturbance and progressive physical decline, which can occur early in the disease, impairing postural control and gait ability

* Corresponding author at: Physiotherapy Department, Royal United Hospital, Combe Park, Bath BA1 3NG, UK. Tel.: +44 1225824293; fax: +44 1225825978.
E-mail addresses: rachaelmalthouse@nhs.net, rachaelwilko@hotmail.co.uk (R. Malthouse).

http://dx.doi.org/10.1016/j.physio.2013.10.002
0031-9406/

[7], resulting in reduced independence in activities [8]. Estimates suggest that over 1.7 million people in the UK will be living with dementia by 2051 [6], with associated cost implications for healthcare and social services. The development of interventions that support or reduce the care needs of this population is therefore critical.

Non-pharmacological interventions, including physical exercise, have attracted attention based on growing evidence of links to a range of physical, psychological and social benefits for people with dementia [9]. A systematic review found some evidence that physical activity slows cognitive decline in people with dementia [10]. A more recent systematic review evaluated the effects of exercise intervention on physical function for people with dementia in residential care, and concluded that combined walking and functional weight-bearing exercise improves walking performance and reduces the rate of decline in functional activities. However, it was unclear whether physical exercise could improve cognitive functions amongst people with dementia, due to the low methodological quality of available studies [2]. The current study aimed to improve understanding about the experiences of physical activity for people with Alzheimer's disease and their spouse carers. The research question was 'What are the barriers and facilitators to physical activity for people with Alzheimer's disease and their spouse carers?'.

The objectives of this study were: to gain insight into perceptions about the importance of physical activity; and to understand potential barriers and facilitators to activity and consider the development of activity interventions that would be acceptable, sustainable and feasible for both people with Alzheimer's disease and their spouse carers.

Design

A qualitative approach was undertaken to explore the experiences of people with Alzheimer's disease and their carers to facilitate in-depth understanding of the relevant issues. Based on an applied healthcare issue, the research was not underpinned by a specific philosophical stance [11], but was guided by inductive thematic analysis which is increasingly viewed as a methodology in its own right [12].

Ethics and research governance

Ethical approval for the study was granted by the South West Ethics Committee and Bath and North East Somerset Primary Care Team.

Participants

A purposeful sampling strategy was employed to identify five pairs of people with Alzheimer's disease and their spouse carers from a memory clinic that was supporting the research. Although small, this number fitted the qualitative framework, where the aim was not to reach saturation but to account for the rich, individual experiences of the people with Alzheimer's disease and their carers, and to identify common themes.

Inclusion criteria for the spouse couple

- One member of the couple has a diagnosis of Alzheimer's disease.
- Person with Alzheimer's disease has some insight into their diagnosis.
- Both able to speak conversational English.
- Both able to understand the research and provide informed consent.
- Living together in a domiciliary setting (not a residential or nursing home).

Procedure

Experienced clinical psychologists, with understanding of issues about capacity and consent, recruited participants. The people with Alzheimer's disease were all involved in clinical drug trials that were unrelated to this research project. Spouse couples who met the inclusion criteria, and who agreed to their contact details being passed on to the primary researcher (RM), were provided with participant information packs. The researcher telephoned them to explain the study, answer questions and arrange a suitable time for the interviews. Five people with Alzheimer's disease and five spouse carers, all aged between 64 and 84 years, were recruited. Mini Mental State Examination scores for people with Alzheimer's disease ranged between 18 and 21 out of 30.

Interviews

Development

One-to-one semi-structured interviews were used to explore the salient issues and address the research question. An interview schedule was developed with input from the project steering group, which included two carers of people with dementia, a consultant geriatrician, two clinical psychologists, a physiotherapist working within the older people's mental health team, a qualitative researcher and an activity co-ordinator from AGE UK. The interview schedule contained open-ended questions about the participant's past and current levels of activity, their understanding of the benefits of activity, ideas about potential activity interventions and implications of having dementia (or caring for someone with dementia) on activity levels. The researcher piloted the interview schedule with volunteers to ensure that the questions were well framed.