

Chapter 69

Carers of People with Dementia and the Use of Assistive Technologies

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ABSTRACT

Assistive technologies have a role in supporting both formal and informal carers of people with dementia. Whilst assistive technologies have a role in maintaining the independence and quality of life of both people with dementia and their carers, their use has both disadvantages and advantages, can pose challenges for all concerned, and raises ethical dilemmas. In this chapter, a model derived from Arnstein's ladder of participation is used to highlight the importance of empowering and connecting with carers in order to increase their participation in the care of their relative or client. Empowerment and connection contribute to maintaining the autonomy and well-being of both carers and people with dementia: technological interventions should not be used as alternatives to connection. The emphasis in practice should be on empowering and connecting with both carers and people with dementia.

INTRODUCTION

In the United Kingdom (UK) currently there are about 800,000 people with dementia, of whom approximately 665,000 live in England. Dementia costs the UK economy £17 billion a year, and, in the next 30 years, the number of people with dementia in the UK will double to 1.4 million, with care costs trebling to over £50 billion per year (Alzheimer's Society, 2007). The care of people

with dementia presents a huge challenge to society now, and demand will increase in the future.

There are approximately six million carers in the UK: 1.4 million of them provide unpaid care for more than 50 hours per week (Office for National Statistics, n/d; The NHS Information Centre Social Care Team, 2010). The work of unpaid carers makes a significant contribution to the UK economy and it is estimated that carers save the taxpayer approximately £119 billion

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per year (Buckner & Yeandle, 2011) equivalent to £2.3 billion per week. Unpaid informal carers are a major part of the system of support for people with dementia. The Alzheimer's Society estimates that there are 670,000 people in the UK acting as primary carers for people with dementia (Alzheimer's Society, 2012), and that carers for people with dementia save the UK over £8 billion per year. Many of the carers of people with dementia are themselves elderly, and may have long-term health conditions or a disability. Two thirds of all people with dementia live in their own homes with unpaid carers providing most of their support. The EURO CARE study (Schneider *et al.*, 1999) found that half of all people with dementia in the community received at least 35 hours of informal care per week.

Although many carers report personal satisfaction from their caring role; it is recognised that unpaid caring has considerable impact on the carer's health and wellbeing and can lead to emotional and physical exhaustion, depression, poor general health and isolation (Alzheimer's Society, 2013a). The Princess Royal Trust for Carers (The Princess Royal Trust for Carers, 2011) found that two thirds of older carers have long term health problems or a disability themselves; one third of older carers reported having cancelled treatment or an operation they needed due to their caring responsibilities; and half of all older carers report that their physical health had got worse in the last year. Four out of ten older carers said that their mental health had deteriorated over the previous year.

The impact of dementia on the families of those with the condition is profound. Dementia results in a progressive decline in multiple areas of function, including memory, communication, language, and in activities of daily living skills (Department of Health, 2009). Moreover, people with dementia may develop behavioural and psychological symptoms (BPSD) such as depression, psychosis, aggression or wandering. BPSD are common, often problematic for carers, and may

be present in almost 80% of people with dementia residing in care environments (Margallo-Lana *et al.*, 2001), complicating care at any stage of the illness. The UK National Dementia strategy highlights the significant effect of BPSD on carers and caring (Department of Health, 2009).

This chapter is divided into four sections. Section One covers formal and informal carers of people with dementia and psychological support for them. Section Two looks into the use of assistive technologies in dementias, advantages, disadvantages and the ethical and moral dilemmas associated with its use. Section Three looks into currently available assistive technologies and how people with dementia and their carers can be empowered using such technologies. Section Four concludes the chapter and emphasizes the importance of not just empowering but also connecting with people with dementia and their carers through the use of assistive technologies.

1. CARERS OF PEOPLE WITH DEMENTIA, FORMAL AND INFORMAL

Family Carers of People with Dementia

Family carers of people with dementia are often old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life (Alzheimer's Society, 2007). Research shows that carers of people with dementia experience greater strain and distress than carers of older people with other long-term conditions (Moise *et al.*, 2004). The Alzheimer's Society reports that 52% of carers of people with dementia are not getting sufficient support to enable them to carry out their caring role and that this has significant repercussions including impact on mental and physical health and premature admissions of people with dementia to long-term care (Alzheimer's Society, 2011).

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