Chapter 6

Awareness, Self, and the Experience of Dementia: Foundations of a Psychologically Minded Approach

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ABSTRACT

It is now widely acknowledged in policy and practice that the individual with dementia retains the status of a person and the essence of selfhood, has the right to be heard, and has the capacity to live well with the disabilities that dementia brings, given appropriate support. Nevertheless, negative assumptions about dementia as a ‘loss of self’ and a ‘living death’ remain influential. This chapter examines research evidence that can provide a foundation for a psychologically minded approach to dementia care and help to create a more constructive view of what it means to live with dementia. In this chapter findings are drawn from projects conducted by the Research in Ageing and Cognitive Health (REACH) group at Bangor University, UK on awareness, self-concept, identity and the experience of dementia for people across the dementia trajectory. The REACH group is now at the University of Exeter, UK.

INTRODUCTION

The stigmatisation and objectification of dementia often stems from a belief that people with dementia have lost global awareness and their whole sense of self. This chapter aims to establish the foundation for a psychologically minded approach to dementia care and create a more constructive view of what it means to live with dementia. After touching on the negative assumptions about dementia, an understanding of the nature of awareness and self will be outlined. These two frameworks will be used to discuss...
the experience of awareness and identity in early-stage, moderate and severe dementia. The evidence cited in this chapter will originate predominately from research conducted by the Research in Ageing and Cognitive Health (REACH) group at Bangor University, U.K. involving people with dementia and their caregivers. The REACH group conducts research relevant to maintaining health in later life and living well with dementia and associated conditions. This research draws on concepts, theories and methods from clinical psychology, social gerontology, neuropsychology, and neuro-rehabilitation.

Awareness can be defined as a reasonable or realistic perception or appraisal of a given aspect of one’s situation, functioning or performance, or of the resulting implications. In this chapter we outline the Levels of Awareness framework, which is useful for conceptualising and understanding the nature of awareness in dementia. In the Levels of Awareness framework, awareness is considered as operating at four levels of increasing complexity: sensory registration, performance monitoring, evaluative judgement, and meta-representation. Research conducted by the REACH group has focussed on awareness in various stages of the dementia trajectory. Additionally, theories of the multifaceted nature of self will be discussed to enable dementia-related changes in self-identity to be explored.

The experience of early-stage dementia will be discussed with reference to awareness, psychological adjustment, self-concept, and maintaining a valued identity. While some researchers have argued that self and identity diminish or are lost as the disease progresses, early evidence from intervention studies suggest that there are opportunities to support self and identity in people with dementia. This has important implications for how we can improve the experience of living with dementia and tailor interventions to provide person-centred care. The experience of living with moderate-to-severe dementia will also be considered in relation to self, identity and awareness. Understanding awareness can provide a route to enhancing the experience of people with severe or end-stage dementia. In an intervention study (AwareCare), care home staff were asked about their perceptions of residents’ awareness and it was found that training staff to observe and identify signs of awareness at the sensory and perceptual level can improve residents’ quality of life.

This chapter will conclude by considering ways of building on retained awareness and supporting self-concept and sense of identity to illustrate how a psychological approach can assist people to live well with dementia across the disease trajectory.

BACKGROUND

Negative Assumptions about Dementia

The term dementia comes from the Latin and literally means “out of mind” or a state of having lost one’s mind (Herskovits, 1995). Many negative consequences follow a diagnosis of dementia but some of those which can be overlooked include the medicalisation, stigmatisation and objectification of the person with the condition. For instance, when discussing the impact of the condition, the focus is often on the experience of caregivers, namely the burden experienced while providing care for the person with dementia. There is often little consideration of what impact this discussion has on the person with dementia. Additionally, in dementia, the self can be affected by stigma as well as by consequences of the illness, and factors such as personality and life history are often not considered when interacting with the person with dementia, which can have a negative impact on self-efficacy (Sabat, 1994). This issue has been given prominence in the theory of malignant social psychology (e.g., Kitwood & Bredin, 1992). In Kitwood’s