

Abstract

In Ireland, age-related illnesses such as dementia are becoming a greater policy concern in line with population ageing. Despite this, dementia-specific policies and practices are still largely under-developed and the preferences and thoughts of people living with dementia are rarely sought. This thesis provides insights into the lived experiences, the health and social care needs and service utilisation of people living with early-stage dementia. It links the 'personal' to the 'political' by placing their experiences within a framework of the Irish health and social care system, hence embedding the personal, lived experiences within the systemic context.

Taking a person-centred and Interpretive Phenomenological approach, in-depth interviews were carried out with 17 people living with early-stage dementia. In 13 cases, care-partners participated in a one-off in-depth interview. These interviews provided contextual information and gave insights into their own experiences of the dementia process. The third data source comprised of interviews with six policy experts; highlighting current policy priorities within dementia care in Ireland and placing themes raised in phase one and phase two of data collection within the present policy context.

Findings from the study show that the meaning of dementia for respondents was often the struggle to maintain self through sustaining existing roles. Respondents often used mechanism such as covering-up, normalising or withdrawing from social interactions to maintain this. Other findings show that there are few formal service responses to people living with dementia. Even where services were available, the respondents were low service users. Reasons given for this were that participants (i) did not perceive their situation as critical enough, (ii) they never used social services before, (iii) they did not know their current entitlements and (iv) there was a stigma attached to using social services. Findings provide valuable data on the lack of a relationship people living with dementia had with the broader health and social care system. The basis of this relationship can be broken down into: (i) the type of model that exists in Ireland (predominantly a medical model); (ii) incentives and currency needed to engage with services (physical ill-health); (iii) diagnosis (or lack thereof) and (iii) their relationship with service providers, which was often very *ad hoc* due to a lack of guidelines on best practice in relation to dementia diagnosis and referral.

Findings offer rich evidence of the issues people living with dementia confront in a system which provides inadequate and often inappropriate supports. This illustrates the resourcefulness and ingenuity many people use to manage and live on a daily basis with a diagnosis of dementia. These findings emphasise the need for formal services where the focus is on disability, rehabilitation and the promotion of the rights of people living with dementia as citizens. The thesis also makes several conceptual contributions and theoretical linkages, primarily in relation to the interaction between the 'micro' level of lived experiences and the 'macro' level of social and health care system characteristics.