

The transition from cognitive impairment to dementia: older people's experiences

Executive Summary

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There are no competing interests.

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Background

Greater awareness of Alzheimer's disease and other dementias in the media is being accompanied by high profile campaigns to raise the awareness of dementia among the public by Alzheimer's Societies around the world. Nonetheless, the increasing testing of cognition among older people is associated with fears about cognitive impairment and anxieties about obtaining a diagnosis of dementia. Two key documents depict this increasing interest from a UK perspective. The first is an authoritative investigation of the social and economic costs of the increases in the numbers of older people with cognitive impairment and dementia. The second is in the *National Dementia Strategy* in England, which has already led to public awareness campaigns to increase early recognition of memory problems or other symptoms suggestive of dementia, calls for increased skills in a broad range of professions, and the introduction of pilot developments, such as Dementia Advisors with liaison roles to help people with dementia to navigate through health and social care. As the *Strategy* notes, society needs to be prepared for this additional demand, not simply by being able to manage numbers, but by providing the information and advice people need prior to, during and after the diagnostic process. It is here, at this process of transition, the individual concerned will be acquiring the identity of a 'person with dementia' both in their own minds and in the views of others. Little is known about the experiences of people with memory problems accessing memory clinics in England or those of their family members. Previous research on this subject took place at a time when 'anti-dementia medication' was not available and public awareness of the possibility of dementia was less widespread.

Aims

The aim of this study was to understand the experiences, expectations and service needs of the person who is becoming the person with dementia, from the perspectives of the older person and their supporter or carer. Our specific objectives were to describe the process, experiences of assessments and encounters with health and other professionals of older people with a recent diagnosis of dementia, and to describe the process from the perspective of people supporting them (carers). We further explored how older people with dementia and their carers understand, access and use services following assessment and diagnosis and how this is affected by treatment decisions and contact with different sources of advice and information. Our final objective was to develop a model of care for older people newly diagnosed with dementia and their carers that promotes integrated and cross agency working and strategies to support self-management during a time of transition.

Methods

The objective of the systematic literature review was to update a review on the topic of disclosure of the diagnosis of dementia to inform the study fieldwork. Initially, in order to identify any existing reviews published since 2004, preliminary pilot searches of key databases and the Cochrane Database of Systematic Reviews (CDSR) were carried out. The main review directly replicated the methods employed by the earlier review. Key electronic databases were searched for relevant sources including OVID Medline, CINAHL, Web of Science, EMBASE, and Sociological Abstracts; which cover medical, nursing, social science and psychological literature. The results of this search were supplemented by hand searching reference lists of the articles retrieved, and by sending an initial bibliography to experts in the field to identify any missing articles. A date limit was imposed according to the previous literature review on this topic carried out, and papers published after 2003 were included.

The exploratory aim of this study necessitated a qualitative research approach. Separate interviews were carried out with 27 people with memory problems as well as 26 key supporters and carers, regarding their perceptions of expectations, experiences and perceptions of the process of assessment and diagnosis. As the research questions of this study were challenging, ethical considerations were central to the study and care was taken to respect confidentiality and anonymity of all participants. Interviews were transcribed and the approach to formal analysis borrowed from the principles of the constant comparative method, as well as using reflective field notes of the researchers. Themes and codes were generated by the researcher at each site independently, and analysis meetings were held regularly to develop these. Thematic tables were drawn up and iteratively revised as the coding developed. Findings were written up in relation to the overarching themes generated and conclusions and implications developed from the findings.

Results

Few people interviewed in this study experienced the system of memory assessment as patient-centred. They felt that they were kept waiting for long periods of time without knowing what was going on, they sometimes experienced tests and assessments as distressing in settings that could be alarming. It is important to note that such experiences are not unique to dementia services but the early recognition of dementia is a key policy goal of the *National Dementia Strategy*. People with other long-term conditions also enter the healthcare systems with unclear problems and symptoms and may experience their assessment and consultations as confused and prolonged. The issues arising for people with possible dementia may be similar but they may also be experienced to a greater degree in the context of people's declining cognitive abilities, the stigma of dementia and possible ageism. These confounding effects may need to be investigated so that healthcare practices can be better tailored to support people, encourage self-management and to develop person-centred models of care.

This study identified five transitions in the experiences of participants: 'Internalising dialogue': the self awareness that something may be wrong; 'Confirming positions': the seeking of confirmation from those closest to the person with memory problems that help is needed; 'Seeking expert advice': disclosing position to professionals (usually GP); 'Being tested': undergoing diagnostic investigations and receiving results; and 'Seeking understanding': from professionals and other sources. Our findings exploring peoples' expectations and hopes revealed that information provision and communication could be improved and that practitioners often, but not always, helped people to make sense of these uncertain times. This study suggests that there may be different needs among those presenting to memory services with early suspicions that something is wrong and those presenting later when memory problems are evident. Services did not always appear to be equipped with person-centred responses to individuals' varying needs and circumstances.

The limitations of this study are that it is confined to four areas which may not be generalisable and that data was provided by participants with memory problems who may have provided incomplete recollections or may have been distressed. This study attempted to minimize the limits of this approach by setting the data in the context of a systematic literature review and exploring generalisability of the findings with National and Local Advisory Groups.

Conclusions

The key challenges identified in the qualitative literature review conducted for this study related to undergoing the transition from a person with memory problems to one living with dementia. These were seen as coming to terms with losses on multiple levels; psychologically, socially and functionally. We found that those authors who pointed to the need for timely identification of people experiencing emotional distress and struggling to cope reported that early specialist help might be beneficial. However, the literature refers to a shortage of specialist services in many countries and notes that psychological therapies may not be easily accessed. There is increasing call for alternative sources of support to be made available via peer support groups or a stepped care model of psychological interventions. Unfortunately, the literature reveals few validated stepped care models of delivering psychological therapies especially in dementia. This study provides new evidence about the experiences of people through the process of transition to a 'person with dementia'. It concludes that the process is sometimes characterised by uncertainty and waiting. These findings suggest that transition is not a linear process. We conclude that professionals are able to provide tailored support to individuals and their carers at this uncertain time if they are better informed of the 'journey' from the insights of those who have undertaken it.

Addendum

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme, and managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO), based at the London School of Hygiene & Tropical Medicine.

The management of the SDO programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Although NETSCC, SDO has conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.