



## Review article

# The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature



Nan Greenwood (PhD)\*, Raymond Smith (PhD)

Kingston University and St. George's University, London, United Kingdom

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## ABSTRACT

Dementia is usually diagnosed in later life but can occur in younger people. The experiences of those with older-onset dementia are relatively well understood but little is known about the experiences of those with young-onset dementia (aged less than 65 years).

This meta-ethnography therefore synthesised qualitative literature investigating the experiences of people with young-onset dementia (YOD). Six electronic databases were searched and 1155 studies were identified, of which eight fitted the inclusion criteria.

These studies were all from Western countries, were mostly recent (2004–2015) and included the experiences of 87 people with YOD. Participants were generally in their fifties or early sixties and were living at home with others. Many reported difficulties both in the process of receiving a diagnosis and afterwards. Diagnosis felt unexpected, 'out of time' and led to changes in self-identity, powerlessness and changes in relationships. Social exclusion was common. Loss of meaningful activity exacerbated a difficult situation. However, the diagnosis did not mean people's lives were over and many with YOD try to regain control by seeking connections with others with the same condition – sometimes a very important source of support.

Overall, people living with YOD face unique social challenges which go beyond those of older people living with dementia and which result in an even greater negative impact on their lives. Interventions that facilitate peer support and allow people with YOD to engage in meaningful activity should be developed and could perhaps be provided by the voluntary sector.

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\* Corresponding author at: Reader in Health and Social Care Service Research, Faculty of Health Social Care and Education, St George's University of London and Kingston University, Room 61, 2nd Floor Grosvenor Wing, Cranmer Terrace, Tooting, London SW17 0RE, United Kingdom.

E-mail address: [nan.greenwood1@gmail.com](mailto:nan.greenwood1@gmail.com) (N. Greenwood).

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## 1. Background

Although dementia mostly affects older people, it can occur in younger people aged 65 years or less where it is variously known as young-onset dementia [1], early-onset dementia [2] or working-age dementia [3].

Young-onset dementia (YOD) is relatively rare. Estimates of prevalence vary but a recent review reported that registry based studies suggest the prevalence of dementia in people aged between 45 and 64 years old lies between 81 and 113 per 100,000 [4]. However, this may be an underestimate because of unexpected timing and relative rarity of YOD [5]. As a result for many people diagnosis may come comparatively late in the disease's progression [6]. Indeed, it is thought that, on average, it takes over one and a half years longer to be diagnosed for people with YOD compared with people with later onset dementia [7,8]. Furthermore, misdiagnosis is not unusual, resulting in further delays in diagnosis [9] with subsequent delays in receiving appropriate support.

The three most common types of YOD are Alzheimer's disease, vascular dementia and frontotemporal dementia (FTD) [10]. Compared to those with later onset dementia, FTD is more common in younger people [11]. Early on, FTD may involve personality changes, challenging behaviour and reduced motivation [12]. Such changes in the person with dementia can be particularly difficult both for those living with the condition and those supporting them [13].

The challenges for unpaid carers of someone with dementia are well documented [14] but arguably the situations of those caring for someone with YOD are particularly difficult because of its timing. For example, most people with later onset dementia have already retired and any children are likely to be grown up, whilst those with YOD are more likely to have relatively young children posing particular challenges for the entire family [15]. In addition, the age of people with YOD means that the symptoms of dementia may lead to loss of employment [2,16]. The implications of unemployment are manifold and include financial, psychological and social consequences, such as changed or difficult family relationships, poor self-esteem and reduced sense of competency and purpose [2,16–18].

Recognition of the challenges faced by those with dementia in general and their families [19] and more specifically YOD has led to the development of support services including education, support groups and counselling [17,20,21]. A recent review focussing on interventions for younger people with dementia and their carers highlighted the value of purposeful activity (often employment based) for both people with YOD and their carers [22]. Benefits included enhanced self-esteem, sense of purpose and increased social contact.

However, although there is a considerable body of synthesised literature exploring the needs and experiences of both people with dementia in general [23] and their family carers [14], there appears

to be no systematic synthesis of the literature exploring the experiences of people with YOD.

This review therefore aimed to synthesise and evaluate qualitative literature relating specifically to the experiences of people with YOD. The primary research question was: What are the experiences of people diagnosed with YOD?

## 2. Review methodology

There are now several well recognised approaches for conducting systematic reviews of qualitative literature. Meta-ethnography [24], a form of interpretative synthesis, is one of the earliest methods and is a well-accepted form of qualitative review [25,26]. It was selected here for several reasons but primarily because it integrates concepts, goes beyond simply summarising data and is intended to develop further concepts and theories. It requires both induction and interpretation and makes explicit direct comparisons between studies and 'translates' concepts across the selected studies [27]. Furthermore, it has been used in syntheses of health research looking at a variety of issues ranging from, for example, medication taking [26] and the experiences of family carers of people with stroke [28].

## 3. Methods

The review followed the Centre of Reviews and Dissemination (CRD) guidelines [29] and was reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [30].

### 3.1. Inclusion criteria and study selection

#### 3.1.1. Inclusion criteria

1. Qualitative or mixed methods, primary research
2. Investigations of the experiences and perceptions of people with YOD (aged less than 65 years)
3. Published in English in peer reviewed journals

#### 3.1.2. Exclusion criteria

1. Quantitative
2. Participants diagnosed with YOD aged 65 years or over
3. Investigations of the experiences of people with LOD and other conditions
4. Experiences of people with YOD and those of family or paid carers not separately described
5. Published in grey literature, non-peer reviewed journals, reviews or opinion publications

Following duplicate removal, all titles and abstracts were screened. Full texts were sourced for all articles fitting the inclusion criteria. This process was conducted by both authors and where disagreements occurred, consensus was achieved by discussion.

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