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Development of an instrument to assess social functioning in dementia: The Social Functioning in Dementia scale

Andrew Sommerlad[a,b,*], David Singleton[a], Rebecca Jones[a], Sube Banerjee[c], Gill Livingston[a,b]

[a]*Division of Psychiatry, University College London, London, UK*
[b]*Camden and Islington NHS Foundation Trust, St Pancras Hospital, London, UK*
[c]*Centre for Dementia Studies, Brighton and Sussex Medical School, University of Sussex, Brighton, East Sussex, UK*

Abstract

Background: Social functioning is a core domain in the life of people with dementia, but there is no accepted instrument to measure it.

Aims: To develop the Social Functioning in Dementia (SF-DEM) scale and test its psychometric properties for assessing social function in people with dementia.

Method: We interviewed people with mild dementia and family caregivers to develop patient and caregiver-rated SF-DEM versions and then refined them through interviews with health care professionals. We tested its psychometric properties in 30 dyads of people with dementia and family caregivers.

Results: Both SF-DEM versions had content validity and demonstrated concurrent validity against a single item rating overall social functioning (patient rated $r = 0.42$, 95% CI [0.07–0.68]; caregiver rated $r = 0.59$, 95% CI [0.29–0.78]). All participants found it acceptable. Analyses showed reliability (test–retest, interrater, internal consistency) and indications of responsiveness to change.

Conclusions: SF-DEM shows promise as a valid, reliable, acceptable measure of social functioning in dementia.

Keywords: Dementia; Social functioning; Assessment tool; Outcome assessment

1. Introduction

Dementia diagnostic criteria specify impairment, in activities of daily living or social function, must accompany cognitive decline [1,2]. Changes in social function, "how individuals associate and interact, both in society at large and their own personal environment" [3], such as loss of interest in previously valued hobbies or changes within close relationships, are distressing to people with dementia [4,5] and their families [6,7], especially when the person with dementia lacks awareness of social changes [8]. Changes in social behavior occur in the early stages of a number of dementia subtypes [9] including Alzheimer's disease [10] and frontotemporal dementia [11]. These changes may be caused by emotion recognition [12] or theory of mind [13] deficits, or disinhibition [14] related to amygdala and frontal cortex network disruption [15]. Lower premorbid social functioning has been reported to increase dementia risk [16–18] and its progression [19]. Social function is therefore central to the diagnosis of dementia and is a core domain when considering etiology and progression and evaluating the effects of interventions in dementia.

Although measures of general function [20] and quality of life [21] include individual questions about social function, there is no validated instrument available to assess social functioning in people with dementia. We therefore aimed to develop a psychometrically sound and acceptable interviewer-administered measure of social functioning in dementia, the Social Functioning in Dementia (SF-DEM) scale, to be completed in a face-to-face interview with the

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*Corresponding author. Tel.: 020 7679 9248; Fax: ■ ■ ■..
E-mail address: a.sommerlad@ucl.ac.uk

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person with dementia (self-report) or their family caregiver (proxy report).

2. Method

Westminster NRES Committee (15/LO/0105) gave ethical approval. We used gold-standard methodology [22] to develop and test the instrument in an iterative process (Fig. 1) in three phases: (1) instrument development—generation of domains and candidate questionnaire items through qualitative interviews with people with dementia and their family caregivers and a structured literature review; (2) expert interviews—qualitative interviews with dementia experts about the test structure and content to refine the draft assessment tools and test content validity; (3) psychometric testing—in structured interviews with people with dementia and their caregivers.

2.1. Instrument development

2.1.1. Setting

We recruited participants from two community-based memory clinics in London, UK.

2.1.2. Participants

We purposively sampled dyads of people with dementia and their family caregiver for a range of demographic and clinical characteristics to cover varied experiences of social changes in dementia. We stopped interviewing when no new content arose (theoretical saturation).

We included English speakers with dementia of any subtype (diagnosed clinically by consultant psychiatrists, then validated by A.S. against DSM-V criteria for major neurocognitive disorder [1]), of mild severity (Mini–Mental State Examination [MMSE] [23] score ≥20). We excluded those with severe physical or other mental illness limiting their participation in the interviews or those who lacked capacity to give informed consent.

We included current, English-speaking, unpaid, main caregivers, over 18 years old, in contact with a person with dementia at least weekly. We excluded caregivers with severe physical or mental illness which limited their participation in the interviews or without capacity to give informed consent.

2.1.3. Procedure

A health care professional approached potential participants during clinical contact. Interested participants, after

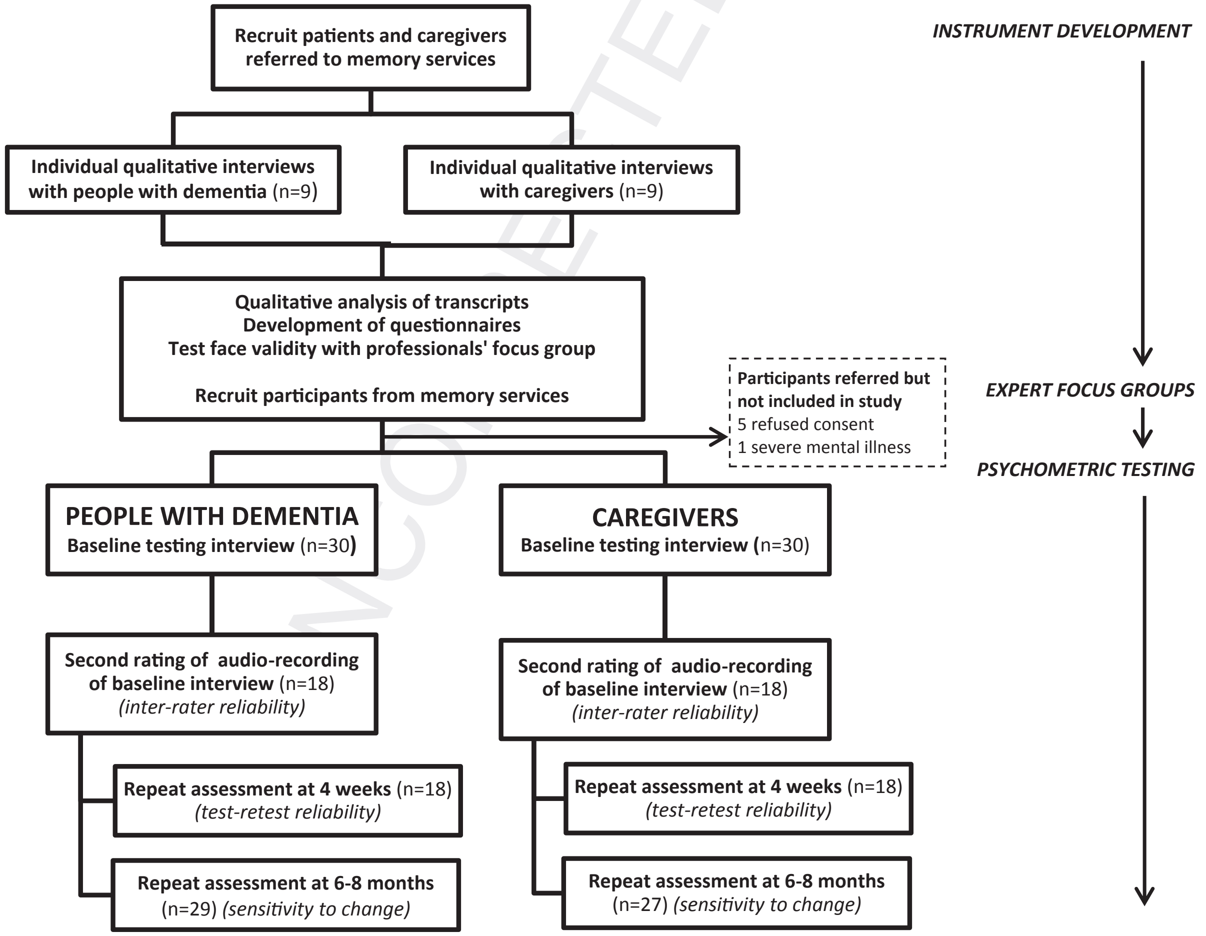

Fig. 1. Overview of study design.