

Summary of Key findings



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A qualitative study to explore how people with early dementia respond to offers of psychosocial interventions

Key findings

Sixteen people with early dementia were interviewed (four alone, 12 with a family carer). Twelve staff participated in a focus group or interview. Participants mostly discussed group cognitive stimulation therapy, education and information groups, memory cafes and 'Singing for the Brain'. Five overall themes identified key influences affecting responses to interventions. These were:

- 1) Adjusting to dementia and self-awareness
- 2) Appeal of interventions and perceived benefit
- 3) Context of services and stigma
- 4) Relationships and trust
- 5) Unmet needs and suggestions for services

Key messages from this research are that acceptance or rejection of interventions was influenced by individual responses to diagnosis, experiences of dementia and dementia services. Self-awareness and adjustment affected whether participants felt they needed interventions. Whether interventions involved activities that appealed and offered perceived benefit also influenced uptake. Interventions offering social contact, peer support, information, enjoyable activities and mental stimulation were valued. But group interventions did not appeal to all, nor did interventions specifically aimed at people with dementia. Stigma seemed to discourage some from accepting interventions. Continuing with community based activities was valued. Ability to travel and convenience of locations also greatly influenced uptake. Emotional and practical support from family carers was vital to acceptance of interventions. Trusting relationships between people with dementia, family carers and staff appeared important facilitators of acceptance.

Project aim: To enhance understanding about the uptake of psychosocial interventions offered or provided by occupational therapists and other professions to people with early dementia and their family members.

Background

Health policy promotes 'living well' with dementia and post-diagnostic support (for example, Department of Health 2009, 2016). Psychosocial interventions and occupational therapy are also recommended by the Memory Services National Accreditation Programme (MSNAP) (Hodge et al 2016).

A growing evidence base suggests that psychosocial interventions can support people with dementia after diagnosis. Occupational therapists can and do offer such interventions, including cognitive stimulation therapy (for example, Streater et al 2016), goal-orientated cognitive rehabilitation (Clare et al 2019) and community occupational therapy (for example, Graff et al 2006) to support activities of daily living, achievement of personal goals, carer competence and quality of life.

However, what influences people with dementia, particularly those with early dementia, to accept psychosocial interventions, to which occupational therapists are often key, is poorly understood. Little research about this topic exists. This research contributes to meeting this knowledge gap by enhancing understanding about what kind of support people with early dementia and family members may want and identifying what enables them to feel ready to engage in psychosocial interventions. Such understanding can help occupational therapists and dementia services develop and target interventions. This is so that people with dementia and families can benefit from the interventions that occupational therapists provide, develop or signpost to.

Methodology

Participants were recruited via NHS memory services and the Alzheimer's Society. A convenience sample was obtained. Face-to-face semi-structured interviews were held with people with early dementia aged over 65, diagnosed within the last two years and living in the community. A choice of solo or joint interview with a family carer was offered to people with dementia. Verbal and visual prompts, allowing plenty of time for responses and to build rapport supported people with dementia to participate. Semi-structured interviews and one focus group were also held with staff. Signed informed consent was obtained from all participants. NHS ethical approval (Ref: REC: 17/NW/0414) and governance approvals were obtained. All interviews were audio-recorded and transcribed. Thematic analysis (Braun and Clarke, 2006) identified key themes. Triangulation (Farmer et al, 2006) enabled integration of findings and identification of overall themes across all the data sources and methods of data collection. Reflexivity was integral to this research (Ormston et al 2014). Field notes were recorded, transcribed and coded during analysis to help interpretation. In particular, I considered the process of joint interviews and whether I had gained the perspectives of participants with dementia. One supervisor coded a proportion of the transcripts to aid credibility.

Recommendations

Audit and/or service evaluations to:

- Identify the type of interventions offered to people with early dementia, when and where.
- Examine reasons for acceptance or rejection of interventions in practice.
- Identify key characteristics (e.g. age, gender, caring relationships/living situation, post code, ethnicity, type of diagnosis) of those who decline to help identify areas for service development.
- Examine whether occupational therapists can or do offer tailored support to address individual needs and goals (for example, those related to social participation and quality of life, as well as safety and risk) in addition to group work.

Consider:

- How to support people with early dementia engage in community based activity, not only interventions aimed exclusively at people with dementia.
- Practicalities when planning interventions, such as venues, location, ease of travel and whether transport provision or support is possible. Familiar, community based venues may encourage uptake.

Consult people with early dementia and carers locally about their ideas for service development.

Publications

Field, B., Coates, E. and Mountain, G. (2019) 'Influences on uptake of a community occupational therapy intervention for people with dementia and their family carers', *British Journal of Occupational Therapy*. SAGE Publications Sage UK: London, England, 82(1), pp. 38–47. doi: 10.1177/0308022618804479.

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References

- Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp.77–101
- Clare, L., Kudlicka, A., Oyebode, et al (2019). Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: A multicentre randomised controlled trial (the GREAT trial). *International Journal of Geriatric Psychiatry*, 34(5)pp 709–721.
- Department of Health (2016) *Prime Minister's Challenge on Dementia 2020 Implementation Plan* https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/505787/PM_Dementia_Acc.pdf
- Department of Health (2009) *Living well with dementia: A national dementia strategy*. London, Department of Health. doi:291591b 1pk http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf
- Farmer, T, Robinson K, Elliott SJ and Eyles J (2006) 'Developing and implementing a triangulation protocol for qualitative health research', *Qualitative Health Research*. Sage Publications Sage CA: Thousand Oaks, CA, 16(3), pp. 377–394
- Graff MJL, Vernooij-Dassen MJM, Thijssen M et al (2006) Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial. *BMJ (Clinical research ed.)*, 333(7580) p.1196.
- Hodge S, Hailey E, Colwill A et al (2016) Memory Services National Accreditation Programme (MSNAP): Standards for Memory Services. London: Royal College of Psychiatrists http://www.rcpsych.ac.uk/PDF/MSNAP_standards_5th_edition_-_web_version.pdf
- Ormston R, Spencer L, Barnard, M et al (2014) The Foundations of Qualitative Research. In J. Ritchie et al., eds. *Qualitative Research Practice. A guide for social science students & researchers*. London: Sage Publications Ltd, pp. 1–25.
- Streeter, A., Spector, A., Aguirre, E. et al (2016) Cognitive stimulation therapy (CST) for people with dementia in practice: An observational study. *British Journal of Occupational Therapy*, 79(12) pp.762–767.