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Effects of Dementia Care Mapping on well-being and quality of life of older people with intellectual disability: A quasi-experimental study

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Abstract

Background: The ageing of people with intellectual disability, accompanied with consequences like dementia, challenges intellectual disability-care staff and creates a need for supporting methods, with Dementia Care Mapping (DCM) as a promising possibility. This study examined the effect of DCM on the quality of life of older people with intellectual disability.

Methods: We performed a quasi-experimental study in 23 group homes for older people with intellectual disability in the Netherlands, comparing DCM (n = 113) with care-as-usual (CAU; n = 111). Using three measures, we assessed the staff-reported quality of life of older people with intellectual disability.

Results: DCM achieved no significantly better or worse quality of life than CAU. Effect sizes varied from 0.01 to −0.22. Adjustments for covariates and restriction of analyses to people with dementia yielded similar results.

Conclusion: The finding that DCM does not increase quality of life of older people with intellectual disability contradicts previous findings and deserves further study.

KEYWORDS
dementia, DCM, effect, intellectual disability, person-centred care, quality of life

1 | BACKGROUND

In the past few decades, the lifespan of people with intellectual disability has greatly increased. In this population, age-related conditions like dementia are experienced earlier and are more prevalent than in the general population (Haveman et al., 2010; Heller & Sorensen, 2013). Moreover, pre-existing deficits and different presentation in adults with intellectual disability make diagnosis of dementia complex. Among people with intellectual disability, its prevalence is estimated to be 18% at the age of 65 (Strydom, Livingston, King, & Hassiotis, 2007). This prevalence is even higher among people with Down's syndrome, 68%–80% of whom have developed dementia by the age of 65 (Coppus et al., 2008; Dekker et al., 2015). In fact, in this group, the average age of onset of dementia is in the early 50s, much sooner than in the general population (Strydom, Chan, King, Hassiotis, & Livingston, 2013; Strydom et al., 2010).

Also in people with intellectual disability, dementia leads to a wide range of changes in memory, functional capacity, communication, neurology, personality and behaviour (Cleary & Doody, 2017). These changes can result in behaviour like agitation, resistance,