



Study healthy ageing and intellectual disabilities: Recruitment and design

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ABSTRACT

Problems encountered in epidemiologic health research in older adults with intellectual disabilities (ID) are how to recruit a large-scale sample of participants and how to measure a range of health variables in such a group. This cross-sectional study into healthy ageing started with founding a consort of three large care providers with a total client population of 2322 clients of 50 years and over, and two academic institutes. This consort made formal agreements about a research infrastructure and research themes: (1) physical activity and fitness, (2) nutrition and nutritional state, and (3) mood and anxiety. Subsequently, preparation was started by carefully reviewing and selecting instruments to measure a wide set of health variables to answer the research questions. Specific demands of these instruments were that they could be executed efficiently and accurately on-site in a large sample of participants and that the burden of these measurements for participants as well as their caregivers was as minimal as possible. Then, preparation was continued by designing and executing a thorough communication plan for clients, legal representatives and staff of the care providers, preceding the informed consent procedure. In this plan, which had a top-down structure, specific attention was given to personally informing and motivating of key stakeholders: the professional care givers. This preparation led to a recruitment of 1050 participants (45.2%) and to high participation rates in key parts of the assessment. A detailed description is provided about the recruitment and organization and the selected instruments.

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1. Introduction

Life expectancy of adults with intellectual disabilities (ID) is lengthening towards that of adults without intellectual disabilities, but daily practice indicates that this ageing is relatively often not a healthy ageing. With a higher risk of motor impairments, sensory impairments and epilepsy since earlier in life, these people are prone to develop multiple physical and mental comorbidities at older age (Davidson et al., 2003; Fisher & Kettel, 2005; Janicki & Jacobson, 1986). 'Frail patients' (multiple diagnoses, complex medical routines, frequent hospitalisation, and functional impairment) (Chess, Krentzman, &

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Charde, 2007), requiring individualised managed care, are expected to be highly prevalent in this population. Furthermore, functional deterioration is frequent (Evenhuis, 1997), leading to diagnostic and therapeutic uncertainty, transfers from community-based to central residential settings, and high costs.

With these risks in mind, three Dutch care organizations (Abrona, Huis ter Heide; Amarant, Tilburg; Ipse de Bruggen, Zwammerdam) and two academic departments (Intellectual Disability Medicine, Department of General Practice, Erasmus MC in Rotterdam; Center for Human Movement Sciences, UMCG, Groningen) intended to start a large-scale project to study health in older adults with intellectual disabilities in 2006. Inspired by questions of the care organizations themselves (formulated by client panels and staff panels), three themes were chosen: (1) physical activity and fitness, (2) nutrition and nutritional state, and (3) mood and anxiety. These themes cover a substantial impact on health and quality of life and are supposed to have strong mutual relationship, but have hardly been studied in ageing people with intellectual disabilities. The scientific aims of this project were: (a) to perform baseline assessments of prevalences and secondary health effects for each theme and to identify risk groups; (b) to assess mutual relationships between the themes and their underlying concepts; (c) to select and evaluate diagnostic tools to assess each theme.

To meet these aims, an observational cross-sectional design was chosen for this multi-center research project. However, before such a study in this particular and complex target population could be executed, two major obstacles needed to be dealt with.

The first obstacle in the execution of such a study is caused by the specific living circumstances of older adults with ID. Many older adults with intellectual disabilities depend on a care system, involving family and professional caregivers. Lack of involvement, commitment and ultimately support by the care system can be an obstacle to recruitment of a large, representative sample, as well as to participation in the assessments which will be a part of the study.

The second obstacle is how to measure a range of health characteristics in older adults with ID. In the general population, preventive health checks are used to collect data about certain health characteristics or risk factors, like the Canadian Study of Health and Ageing (Eastwood, Nobbs, Lindsay, & McDowell, 1992), or the Cardiovascular Health Study (Fried et al., 1991). This kind of screening is not applicable to the population of older adults with intellectual disabilities because self-report questionnaires, neuropsychological tests and often physical tests may require a certain level of cognitive and physical abilities which may not be compatible with those of older adults with intellectual disabilities.

Because of such barriers, most published epidemiological research in adults with intellectual disabilities is based on existing (medical) records or registries, or observations of professional caregivers (Cooper, 1998; Minihan & Dean, 1990; Perry et al., 2010; van Schrojenstein Lantman-De Valk, Metsemakers, Haveman, & Crebolder, 2000; van Schrojenstein Lantman-de Valk et al., 1997; Whitfield, Langan, & Russell, 1996). With this method, underrecognition of certain health problems or risk factors is to be expected (Janicki et al., 2002), due to communication difficulties of the participants and lack of suitable diagnostic instruments. Another solution is to limit the number of participants (Wilson & Haire, 1990). With this solution, extrapolation of the results is hampered since the number of participants is often limited or narrowed by strict exclusion criteria, thus often underestimating the actual problems in this group (Prasher and Janicki, 2002).

This gives rise to the following research question: how to successfully measure health in older adults with intellectual disabilities in a large, representative sample?

2. Materials and methods

Before starting the actual study, measures were taken to ensure optimal circumstances for executing a large-scale study. Therefore, the formation of a consort and description of the base population will be presented first. The method section then proceeds with a detailed description of the selection of instruments and organization of measurements, after which the standard informed consent procedure is described. Subsequently, extra activities undertaken to optimize recruitment will be described, such as extra activities in communication and consent procedures. Inclusion, representativeness and participation are described as main outcome measures.

2.1. Founding a consort

Former research has shown the importance of cooperation and commitment of different management levels to provide the necessary conditions for a successful execution of a large-scale study in the field (Evenhuis et al., 2004; Meuwese-Jongejeugd et al., 2005; Sjoukes, Harteloh, & Evenhuis, 2006). For this reason, three large care providers and two academic departments joined together in a consort, and preparation of a first large-scale study was started at CEO level in 2006. Formal agreements were made about financing and grant acquisition, responsibilities, communication, project management and infrastructure, involvement of clients and client representatives. Agreement was reached on the following aims of the consort: (1) to increase knowledge on healthy ageing in intellectual disability by means of scientific research, (2) to increase the scientific attitude of staff of care providers by means of participation in research and continuous education, and (3) innovation of care by means of implementation of research outcomes. In the preparatory phase and during the execution of the study, the consort discussed about policy, practical issues, results and future directions on three management levels: CEO-level, level of the boards of directors, and middle-management level, to ensure embedding of and commitment to this project.

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