Research Paper

Drop-out during a randomized trial with adolescents with intellectual disability was associated with participant burden, while drop-out at study exit was associated with carer and household characteristics

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ABSTRACT

Background: People with intellectual disability are difficult to retain in longitudinal studies. Research on determinants of study retention for individual-carer dyads, and their reasons for drop-out, are limited.

Aims: To investigate characteristics associated with drop-out, and to investigate whether characteristics varied by stage of drop-out.

Methods and procedures: Data are from an Australian randomized trial with adolescents with intellectual disability living in the community. Characteristics of both the adolescent and their nominated carer were collected at baseline. Carers were sent an exit questionnaire approximately two years after enrolment.

Outcomes and results: Baseline information was available for 566 adolescents: 72(13.0\%) withdrew during the study, and 96(17.3\%) didn’t return exit questionnaires. Characteristics associated with drop-out during the study were being in the intervention group, the carer being younger, and the carer not being one of the adolescent’s parents. Characteristics associated with withdrawal at exit were carer having lower education and carer having lower socioeconomic status. No adolescent characteristic was associated with drop-out.

Conclusions and implications: Characteristics of drop-outs weren’t related to the adolescent and differed according to timing. Drop-out during the study was associated with study burden, whereas characteristics of drop-outs at exit interview were associated with lower social position.

What this paper adds

Few large population-based studies looking at the health of people with intellectual disability have been conducted. Given the difficult-to-recruit nature of this population, the retention of participants is particularly important both in terms of the optimal use of study resources and enhancing the validity of results. In a study of school-attending Australian adolescents with intellectual disability who were followed for two-years, the participants who dropped out during the study were more likely to do so because of high study burden, whereas failure to return exit questionnaires was associated with characteristics of the adolescent’s carer, but not the adolescent themselves. In particular carers were less likely to respond if they were younger, of lower social position, were less
educated, or were not the adolescent’s parent. To reduce participant drop-out in this population, researchers should design studies with as little participant burden as possible, and in intervention studies should ensure the proposed intervention is not so onerous that it will lead to larger drop-out than among participants in the control group. When response is based on paper-based questionnaires, extra resources to encourage return should be based on the characteristics of the adolescent’s carer, rather than on characteristics of the adolescent.

1. Introduction

People with intellectual disability have poorer health and shorter lifespans than the general population, as well as high levels of unrecognized disease and inadequate health screening and promotion (Cooper et al., 2006; Emerson et al., 2012; Heslop et al., 2014). Despite this health disparity few large epidemiological studies concerning the health of people with intellectual disability have been conducted (Brooker et al., 2015; Feldman, Bosett, Collet, & Burnham-Rios, 2014). Recruitment and retention in this population is logistically difficult and resource intensive compared to their peers in the general population (Lennox et al., 2005; Lewis, 2014). Extra difficulties include the need for proxy consent when the individual does not have the capacity to provide informed consent (Iacono & Murray, 2003), the number of gatekeepers that may need to be approached including clinicians, support workers and family members and carers (Lewis, 2014), and, should the disability have a genetic cause, the increased likelihood that the family member providing consent may have limited literacy skills. The extensive recruitment efforts required can be expensive making it more financially important to retain participants than in studies of non-disabled populations.

The topic of participant retention in longitudinal studies has received a significant amount of attention in the past decade. For example in the general population, participation retention is associated with female gender (Dunn, Jordan, Lacey, Shapley, & Jinks, 2004; Eagan, Eide, Gulsvik, & Bakke, 2002; Hille, Elbertse, Gravenhorst, Brand, & Verloove-Vanhorick, 2005), higher education (Burg, Allred, & Sapp, 1997; Hille et al., 2005), older age (Burg et al., 1997; Dunn et al., 2004), being married (Partin et al., 2003), and belief in the importance of the studied topic (Ulrich et al., 2012); while strategies that successfully increase retention rates include extra participant contact, offering participants unconditional incentives, and pre-notification phone calls (Trewick et al., 2010). However there is little published information available on study retention in people with intellectual disability (Cleaver, Ouellette-Kuntz, & Sakar, 2010). In particular it is not known whether the characteristics of the person, or their carer, or both, are most likely to influence the likelihood of successfully completing the study. In order to retain participants and their carers in research studies, and hence maintain a study’s internal validity, it is important to know what factors are likely to be associated with retention, so that some categories of participants can be specifically targeted for cohort maintenance.

An Australian academic research center has run a large randomized trial investigating a health intervention package in adolescents with intellectual disability living in the community. At study entry the adolescent’s nominated carer completed a questionnaire survey. The same carer was invited to complete a follow-up questionnaire at study completion approximately two years later. The aim of this study was to assess the association between adolescent and carer characteristics and participation at follow-up.

2. Material and methods

The Ask Study is a parallel-group cluster randomized controlled trial undertaken among adolescents with intellectual disability attending secondary school and living in the community in Southern Queensland, Australia, between February 2007 and June 2010 (ClinicalTrials.gov identifier: NCT00519311) (Lennox et al., 2012). Adolescents eligible to participate in the Ask study were identified through their enrolment at a Special Education School (SES) or Special Education Unit (SEU). SEEs are segregated and are attended by children with more significant care needs, while SEUs are located on the campus of a mainstream school. Participants had been assessed by Education Queensland to have an intellectual disability, and were aged 10–18 years on 1 January 2006. The intervention assessed was a health intervention package, comprising classroom-based health education, a health check, and a health diary for use by the adolescent, their parents/carers and GPs, compared with usual education and medical care. Units of randomization were schools. Ethics approval was granted by both the University of Queensland Behavioral and Social Sciences Ethical Review Committee (#2004000081) and the Queensland Government Department of Education and the Arts (#550/27/424). Individual consent to participate was gained from the adolescent’s carer.

Baseline questionnaires were sent to the adolescent’s carer upon study enrolment. Exit questionnaires were sent approximately two years after baseline to the last known address of carers who had not withdrawn during the course of the study. Schools were contacted for updated contact details when necessary. Participants were categorized according to their stage of drop-out as either returned exit questionnaire, failed to return exit questionnaire, or withdrew before exit questionnaire was distributed.

Telephone interviews were offered at baseline to allow for parents with low literacy for whom responding to a paper-based questionnaire might be problematic. Questionnaires were posted to the participant’s residential address. Four weeks after the initial mail-out study staff began making follow-up phone calls to prompt potential participants to return their questionnaires. All carers who had not responded received at least two reminder calls. When carers were contacted by phone the option of a telephone interview was offered (either immediately or at a time of the carer’s choosing). Carers were not systematically targeted for telephone interview. Baseline return status was categorized as either postal returner (returned questionnaire without phone call), postal returner after phone prompt or telephone responder (completed questionnaire by telephone).

The baseline and exit questionnaires were the same for both intervention and usual care groups, with the addition of questions regarding the usability and benefits of the health intervention package for the intervention group in the exit. Baseline questionnaires asked the age and sex of the adolescent, the etiology of their intellectual disability, and their abilities, and for an assessment of their
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