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Proxy and self-reported Quality of Life in adults with intellectual disabilities: Impact of psychiatric symptoms, problem behaviour, psychotropic medication and unmet needs

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ABSTRACT

Proxies often underestimate the subjective Quality of Life (QoL) of adults with intellectual disability (ID). However, little is known about the reasons for these differences. Accordingly, the purpose of the present study is to, firstly, compare the self-reported QoL of adults with ID with proxy reports from staff of sheltered working and housing facilities, and, secondly, to identify possible differences of the impact of four potential predictor variables. Data of 102 adults with ID were collected as part of the MEMENTA study (‘Mental health care provision for adults with ID and a mental disorder’). Results show that self-report QoL scores ranged from 72.6 to 86.8. Both proxies consistently reported lower QoL scores and agreement between self and proxy ratings was predominantly poor. Unmet needs and psychotropic medication were identified as the most important predictors of reduced self-rated QoL, whereas an increase of psychiatric symptoms, problem behaviours, and psychotropic medication best predicted the reduced QoL proxy ratings. To conclude, proxies still have to strive for a more holistic approach in surrogate QoL assessments and according to adults with ID, service providers should focus on a reduction of unmet needs and psychotropic medication to further improve QoL.

1. Introduction

1.1. Quality of life self and proxy reports

Quality of Life (QoL) is often used as an outcome parameter in the evaluation of services provided for people with intellectual disability (ID; Townsend-White, Pham, & Vassos, 2012). It is defined as the “individuals’ perceptions of their

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position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1995). Thus, objective criteria, such as chronic health constraints, do not necessarily result in lower QoL per se; moderating variables such as personal values, aspirations, and expectations (Felce & Perry, 1995), and intrapersonal and interpersonal variability (Schalock et al., 2002) need to also be considered. Accordingly, there is broad agreement that self-reported QoL is preferable to proxy reports (White-Koning et al., 2005). However, in adults with ID, sometimes self-rated QoL might not be obtainable, such as due to limited communication skills or a profound level of ID. In such cases, proxy QoL ratings remain the only available source of information (White-Koning et al., 2005).

To assess whether proxy ratings are a valid alternative to self-reported QoL in people with ID, self and proxy reports have been compared in several studies. Results range from low (e.g., Zimmermann & Endermann, 2008) to moderate (e.g., Balboni, Coscarelli, Giunti, & Schalock, 2013; Claes et al., 2012; Schmidt et al., 2010) to high agreement (e.g., McVilly, Burton-Smith, & Davidson, 2000). A common finding across most studies, however, is that relatives, professional carers, and clinicians tend to rate the QoL of the person with ID lower than the person with ID themselves (e.g., Zimmermann & Endermann, 2008). Furthermore, agreement in more observable aspects of QoL (e.g., physical activity, functioning, symptoms) is usually higher compared to agreement in more subjective aspects (e.g., social, emotional, psychological domains; White-Koning et al., 2005). Such differences between self and proxy rated QoL are not ID specific, but are also found in other areas of health (cf. in patients with chronic disease (Sneeuw, Sprangers, & Aaronson, 2002) or in patients with dementia (Arlt et al., 2008). Knowledge about the reasons for these different assessments is minimal.

1.2. The impact of mental health and unmet needs on quality of life reports

In recent debates about programme planning and evaluation in the field of ID one of the key components, is the provision of individualized supports within inclusive environments (Schalock, Bonham, & Verdugo, 2008). To provide individualized supports, the perceived effect of different factors on QoL self and proxy reports needs to be analyzed. A specific set of predictors has repeatedly been found to be associated with ratings of QoL: Health status (i.e., mental or physical well-being), problem behaviour, and perceived social support (Schalock, 2004).

It is well known that mental health problems have a major effect on general well-being and QoL (Devine, Taggart, & McLornian, 2010), yet there are currently no studies examining the impact of *psychiatric symptomatology* of adults with ID on QoL proxy reports. In a recent study, Endermann (2013) found that psychological distress accounted for 17.0% of the variance in self-reported global QoL. Psychological distress was the strongest predictor of both impaired health-related and global QoL in individuals with epilepsy and mild ID.

The impact of *problem behaviour* on QoL is embedded in the definition of problem behaviour by the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD; Royal College of Psychiatrists, 2001) in the third mandatory criterion. Thus, problem behaviour must either have a 'significant negative impact on the person's QoL or QoL of others' or is a 'significant risk to the health and/or safety of the person and/or others' (Royal College of Psychiatrists, 2001). Schwartz and Rabinovitz (2003) found that low ratings of problem behaviour were associated with significant higher life satisfaction staff ratings compared to self-ratings of the people with ID. However, no significant interaction emerged when the people with ID had high scores of problem behaviour (Schwartz & Rabinovitz, 2003).

Another factor that has consistently been associated with QoL is the number of *unmet needs*. Among psychiatric patients, higher self-reported QoL was associated with having fewer unmet needs, both self and proxy reported when compared with other predictors (Slade et al., 2004). Renty and Roeyers (2006) found that the number of unmet needs was negatively correlated with self-reported life satisfaction in individuals with high-functioning autism. Lasalvia et al. (2005) showed that a reduction in psychiatric patient rated unmet social needs measured by the Camberwell Assessment of Need (CAN; Phelan et al., 1995) predicted an improvement of self-rated QoL over 4 years. This relationship, however, was not evident for needs as rated by staff. Yet, QoL and perceived needs are influenced by individual values, expectations, culture, and socioeconomic and other factors (Andresen, Caputi, & Oades, 2000).

Psychotropic medication is often prescribed in people with ID (Deb et al., 2009; Holden & Gitlesen, 2004). The effect of psychotropic medication on QoL of patients with ID and mental disorders/behavioural problems may sometimes be negative and this should be taken into account when prescribing psychotropic medication (Lalor & Poulson, 2013). Negative side-effects of psychotropic medication (e.g., extra-pyramidal side-effects, hypertension, decreased sleep, hyperactivity, or withdrawal) may result in negative effects such as frustration or helplessness that further limit the perceived QoL of the adult with ID (Lalor & Poulson, 2013). Tsiouris (2010) concludes that a change in current antipsychotic prescription practice might improve the QoL for many persons with ID. Nevertheless, empirical studies examining the effects of psychotropic medication on QoL in individuals with ID are scarce.

1.3. The present study

The purpose of this study is twofold. Firstly, this study explores the level of agreement between self and proxy reports on subjective QoL by comparing self-reports of adults with ID with proxy reports of professional carers from sheltered workshops and from the living environment of the adult with ID. Secondly, this study tries to identify reasons for presumed