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An initial assessment of the psychometric properties of the Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID)

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ABSTRACT

Given the research evidence that people with intellectual disability (ID) do grieve following bereavement, the present study aimed to describe and gather preliminary psychometric data for a version of the Inventory of Complicated Grief [Prigerson, H. G., Maciejewski, P. K., Reynolds, C. F., Bierhals, A. J., Newsom, J. T., Fasiczka, A., et al. (1995). Inventory of Complicated Grief: A scale to measure maladaptive symptoms of loss. *Psychiatry Research*, 59, 65–79] adapted for use with this population. Carers completed the Complicated Grief Questionnaire for People with ID (CGQ-ID) for 76 individuals with ID, half of whom had experienced a parental bereavement within the last 2 years. The final scale and subscales (Separation Distress and Traumatic Grief) showed very good internal and inter-rater reliability and distinguished between the two groups. While the findings suggest that the CGQ-ID is suitable for identifying complicated grief-type symptoms among adults with ID, further research must be conducted to ascertain whether the findings can be replicated.

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1. Introduction

As people with intellectual disability (ID) are living longer, more and more will experience significant life events such as bereavement. At the same time, there is a growing body of evidence from bereavement research that suggests that pathological grief symptoms (e.g. intense prolonged experience of disbelief, depression, anger and yearning) represent a distinct clinical entity within the general population (Prigerson, Vanderwerker, & Maciejewski, 2008). Within this context, there is a movement to see 'pathological grief disorder' included in the fifth edition of the *Diagnostic and Statistical Manual for Mental Disorders* (Prigerson et al., 2008). In an effort to add to our understanding of the symptoms that may be associated with pathological or complicated grief in the general population, an assessment tool in the form of an Inventory of Complicated Grief has been developed (Prigerson et al., 1995; Prigerson et al., 1999). The inventory uses symptoms taken from existing psychopathology and grief symptom inventories (Frank, Prigerson, Shear, & Reynolds, 1997) and includes separate subscales of Separation Distress and Traumatic Distress. The Inventory of Complicated Grief has been used with a number of groups and its psychometric properties have been found to demonstrate good internal consistency, as well as convergent and criterion validity, and was found to be an easily administered assessment for symptoms of complicated grief (Prigerson & Jacobs, 2006).

However, recognising the potential for grief reactions in the ID population, no assessment tool has been developed for with people with ID. This is a significant gap, given that there is clear evidence to show that people with ID experience feelings of grief and sadness following a bereavement (Dowling, Hubert, & Hollins, 2003) and their behaviour and mental health can deteriorate as a result (Dodd, Dowling, & Hollins, 2005; Hollins & Esterhuyzen, 1997). Despite the growing body of research in this area specifically, there is still a paucity of information and understanding of the symptoms that people with ID experience, as well as a lack of appropriate methods of assessment. Research by Blackman (2008) describes a tool for the assessment of support needs among this group following a bereavement, but this does not consider the issues associated with complicated grief. If professional carers and staff in organisations are to be able to support individuals who are experiencing a complicated grief reaction, it is essential that valid and reliable assessment tools are available.

However, there are significant difficulties associated with researching the effects of a significant life event such as bereavement, on people with ID. First, people with ID are not a homogenous group: there are wide differences in experience, environment, personality, and ability. Secondly the grief questionnaires that are used in the general population are frequently not appropriate for use in this population because of their complexity of language and concepts used in them; examples include the Texas Revised Inventory of Grief (TRIG) (Faschingbauer, 1981), the Grief Experience Inventory (Sanders, Mauger, & Strong, 1985) and the Inventory of Complicated Grief (Prigerson et al., 1995). Therefore there is a need to develop tools that are appropriate for use with this population.

The Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID) is an adapted version of the Inventory of Complicated Grief (Prigerson et al., 1995). The Prigerson scale was selected for adaptation as it was believed to offer the best opportunity to explore the full range of grief reactions, up to and including more pathological forms of grief. Given the paucity of the research in this area, the challenges associated with developing self-report measures in ID, and the sensitive nature of discussing these issues with service users, the tool was initially developed as a proxy-report measure. This will allow for an initial assessment of the validity of the symptoms of complicated grief in the population and the potential of the scale to inform research in this area. Therefore the aim of this study is to describe the CGQ-ID and evaluate the psychometric properties of the tool.

2. Method

2.1. The adapted questionnaire

The CGQ-ID is a modified version of the Inventory of Complicated Grief (Prigerson et al., 1995). The original questionnaire explores all of the possible symptoms (including symptoms of Traumatic Grief

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