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Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables



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ABSTRACT

Studies have shown that stigmatization is linked to lower quality of life; however, only scant research has examined the association between family caregivers' internalization of stigma (affiliate stigma) and their subjective quality of life (subjective well-being, SWB). Furthermore, studies have rarely examined this association via comparison between caregivers of individuals with different developmental disabilities in addition to examining the influence of psychosocial protective factors. These were the aims of the current study. Family caregivers ($N = 176$) of individuals with autism spectrum disorders (ASD), intellectual disabilities (ID), and physical disabilities (PD) completed a self-report structured questionnaire including scales measuring SWB, affiliate stigma, burden, positive meaning in caregiving, social support and self-esteem. Results showed that SWB of family caregivers was below the average normative level and especially low for caregivers of individuals with ASD. The strongest predictors of SWB were caregivers' self-esteem, social support, positive meaning in caregiving, and affiliate stigma. Furthermore, an interaction was found between affiliate stigma and diagnosis, showing that among caregivers of individuals with ASD, greater levels of stigma were associated with lower ratings of SWB, whereas such an association was not found among caregivers of individuals with ID or PD. Findings from this study point to the importance of supporting caregivers across the life-span in order to decrease stigma, improve social support and self-esteem and improve SWB. Further, findings point to the need to respond differentially to the various developmental disabilities.

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1. Introduction

A great deal of research has shown that raising a child with a developmental disability (DD) strongly impacts family caregivers and especially parents (Samuel, Rillotta, & Brown, 2012). Early research has shown an association between caring for a child with a DD and chronic sorrow among the parents (Olshansky, 1962). While most research has moved away from the perception of chronic sorrow, it is nevertheless recognized that the economic, psychological and social burden of caring for a child with a DD may strongly affect the quality of life (QoL) of the parents (Isa et al., 2013). Given that families are recognized as crucial for the well-being of children with disabilities, researchers, service providers and policy makers have recognized the importance of supporting them and of providing the means to have a positive QoL (Samuel et al., 2012).

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QoL is a broad concept which can be assessed through either objective or subjective measures. Objective measurement of QoL includes, for example, objective circumstances of living, number of friends and degree of physical disability (Cummins, Mellor, Stokes, & Lau, 2010), whereas the subjective dimension of QoL, which has been referred to as subjective well-being (SWB), includes, for example, the degree of perceived happiness or satisfaction. Theorists and researchers recommend focusing on the subjective aspect of QoL (Cummins et al., 2010), mainly because it allows for a global and comprehensive examination (McGillivray, Lau, Cummins, & Davey, 2009), which cannot be attained with more objective measures, for example, the International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2001).

SWB is defined as a normally positive state of mind that involves the whole life experience and encompasses life satisfaction and happiness (Cummins et al., 2010). Although subjective, a psychological/neurological system of SWB homeostasis has been posited in which people strive to maintain normal levels of well-being even under difficult conditions, with an average set-point of 75 on a 100-point scale (Cummins, 2000; Cummins et al., 2010). SWB may drop below this set-point range in situations in which the level of challenge to SWB becomes too great (Cummins et al., 2010).

Several variables have been found to be related to the QoL of caregivers of individuals with disabilities. These include challenging caregiving demands (Larson, 2010), burden from insufficient family support, health status of parent and household income (Lin et al., 2009). However, one variable which has rarely been examined in relation to QoL of caregivers of individuals with DD is caregiver's affiliate stigma.

1.1. Stigma, affiliate stigma and quality of life

Stigma is conceptualized as a set of prejudicial attitudes, stereotypes, discriminatory behaviors and biased social structures endorsed by a sizeable group about a discredited subgroup (Corrigan, 2000). Three over-arching types of stigma have been conceptualized. The first and most well-known type of stigma is public stigma, which focuses on the attitudes of the general population toward stigmatized persons (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). The second type of stigma is self-stigma, which focuses on individuals' internalization of society's negative views toward themselves (Corrigan & Watson, 2002). The third type of stigma is family stigma, which is the stigma experienced by individuals as a consequence of being associated with a relative with a stigmatic mark (Goffman, 1963; Larson & Corrigan, 2008).

Lately, Mak and Cheung (2008) have differentiated between the stigmatic perceptions of the public about family caregivers (i.e. family stigma) and the internalized stigma of these family members, which has been termed *affiliate stigma*. Thus, affiliate stigma focuses on the extent of self-stigmatization as experienced by associates of targeted individuals and the corresponding psychological responses of these associates.

Research regarding affiliate stigma and SWB is scant. Most available literature concentrates on the more general construct of family stigma and focuses almost exclusively in the area of mental illnesses, showing that higher awareness of stigmatization in family members of persons with mental illnesses is associated with lower QoL (Angermeyer, Beck, Dietrich, & Holzinger, 2004; Dinos, Stevens, Serfaty, Weich, & King, 2004).

The current study intends to expand this narrow body of knowledge by examining the construct of affiliate stigma among family caregivers of individuals with DD and its relationship to their subjective evaluation of QoL.

1.2. Developmental disabilities, stigma and SWB

Developmental disability is defined as a severe and chronic disability which originated at birth or during childhood, and which is attributable to a mental or physical impairment or to a combination of both. Further, it is manifested before the individual attains age 22, is expected to continue indefinitely and substantially restricts the individual's functioning in several major life activities (Developmental Disabilities Assistance and Bill of Rights Act, 2000).

The aim of the present study was to examine the relationship between affiliate stigma and caregivers' SWB among family caregivers of individuals with three types of DD – intellectual disability (ID), autism spectrum disorders (ASD) and physical disabilities (PD). This examination is important as it has been shown that disability type and history of aggressive behavior play an important role in attitude formation (Tsang, Chan, & Chan, 2004). Indeed, several studies have consistently shown that more positive attitudes are reported toward people with PD than toward individuals with mental disabilities (Cook, 1998; Wong, Chan, Cardoso, Lam, & Miller, 2004). However, to the best of our knowledge, it remains to be examined whether these differences are internalized among caregivers and translated into affiliate stigma.

Indeed, in the area of DD, only a few studies have examined the association between family stigma and SWB. For example, Chou, Pu, Lee, Lin, and Kroger (2009) in a study assessing 416 caregivers of adults with ID or mental illness, found that caregiver's feelings of shame had an adverse impact on their QoL, with a stronger effect among carers of adults with mental illness. The authors suggested that this effect might be the result of ID eliciting more sympathy than mental illness. A different study conducted among 188 caregivers of individuals with ASD in China (Mak & Kwok, 2010) showed that experiencing stigma led to its internalization, which was negatively correlated with caregivers' psychological well-being.

Despite the importance of previous studies, only three (Chiu, Yang, Wong, Li, & Li, 2013; Mak & Cheung, 2008; Mak & Kwok, 2010) examined the specific concept of affiliate stigma; a fourth (Chou et al., 2009) examined related notions, such as shame, but did not utilize the specific concept of affiliate stigma. Moreover, two of these studies examined affiliate stigma, but not its association with SWB or QoL (Chiu et al., 2013; Mak & Cheung, 2008). Furthermore, all these studies were conducted solely in China or Hong Kong and focused on ASD (Mak & Kwok, 2010) or ID (Chou et al., 2009), without providing

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