

## Health-Related Quality of Life—From the Perspective of Mothers and Fathers of Adult Children Suffering From Long-Term Mental Disorders

Anita Johansson<sup>a,b,\*</sup>, Mats Ewertzon<sup>c,d</sup>, Birgitta Andershed<sup>e,f</sup>, Agneta Anderzen-Carlsson<sup>a,g</sup>, Salmir Nasic<sup>h</sup>, Arne Ahlin<sup>i</sup>

<sup>a</sup> School of Health and Medical Sciences, Örebro University, Örebro, Sweden

<sup>b</sup> Division of Psychiatry, Skaraborg Hospital, Skövde, Sweden

<sup>c</sup> Department of Health Care Sciences, Ersta Sköndal University College, Stockholm, Sweden

<sup>d</sup> Swedish National Family Care Competence Centre, Kalmar, Sweden

<sup>e</sup> Department of Palliative Care Research, Ersta Sköndal University College, Stockholm, Sweden

<sup>f</sup> Department of Nursing, Gjøvik University College, Gjøvik, Norway

<sup>g</sup> Centre for Health Care Sciences, Örebro, Sweden

<sup>h</sup> Research and Development Centre, Skaraborg Hospital, Skövde, Sweden

<sup>i</sup> National Board of Institutional Care, SiS Ungdomshem Margretelund, Lidköping, Sweden

### A B S T R A C T

There is a lack of studies on mothers' and fathers' experiences of Health-Related Quality of Life (HRQOL) associated with caregiving of adult children suffering from mental disorder. A cross-sectional study was therefore carried out with 108 mothers and 43 fathers. Data were collected by means of the Short Form Health Survey (SF-36), the Hospital Anxiety and Depression Scale (HADS), the Family Involvement and Alienation Questionnaire (FIAQ) and the Burden Assessment Scale (BAS). Mothers' HRQOL was affected more than fathers' and lower compared to Swedish age related norms. HRQOL was predominantly related to ratings on HADS and BAS.

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Parents of children with long-term mental disorders are affected in their role as parents and individuals. Studies have shown that parents of adult children with a mental disorder report emotional and practical experiences that have an impact on their psychological well-being (Aschbrenner, Greenberg, & Seltzer, 2009; Clarke & Winsor, 2010; Foldemo, Gullberg, Ek, & Bogren, 2005; Godress, Ozgul, Owen, & Foley-Evans, 2005). These burdensome experiences are often associated with a perceived loss of the child's personality and potential (Foldemo et al., 2005; Wiens & Daniluk, 2009) as well as difficulties in their personal and professional life compared to other parents (Aschbrenner et al., 2009). Furthermore, parenthood has been described as an overwhelming grief (Ferriter & Huband, 2003; Godress et al., 2005; Howard, 1998; Pejler, 2001) and associated with difficulties sharing their experiences with friends because of fear of being judged (Clarke & Winsor, 2010).

Lack of collaboration between mental health professionals and parents meant that the latter did not receive important information (Ferriter & Huband, 2003; Jakobsen & Severinsson, 2006; Johansson, Andershed, & Anderzen-Carlsson, 2014; Knudson & Coyle, 2002), nor were the professionals effective in seeking and obtaining information about the children from parents (Clarke & Winsor, 2010; Nyström &

Svensson, 2004). It has also been reported that professionals lack understanding of parental needs and that parents' ambitions for their children are either questioned or not properly considered (Reid, Lloyd, & de Groot, 2005). This approach could result in feelings of inadequacy in parenthood and perceived lack of skills (Nyström & Svensson, 2004). Furthermore, Rusner (2012) described the importance of paying attention to the individual needs of persons with mental disorders and their relatives. The view of mental healthcare has changed and now comprises consensus, collaboration and transparent communication between the person suffering from a mental disorder, her/his relatives and professionals.

In most cases, mothers of children suffering from mental disorders have participated in studies, yet regardless of the proportion of mothers and fathers they have been referred to as "parents" (Clarke & Winsor, 2010; Foldemo et al., 2005; Godress et al., 2005; Reid et al., 2005). Studies of both mothers' and fathers' perspectives have found that mothers suffer from higher levels of stress and burden (Pruchno & Patrick, 1999; Wancata et al., 2008) and have a greater need for support than fathers (Wancata et al., 2008). On the other hand, fathers usually ask for support from their wives (Johansson et al., 2014; Wintersteen & Rasmussen, 1997). The need for support and advice is thus expressed by both mothers and fathers.

### RATIONALE FOR THE STUDY

Although it is commonly acknowledged that the burden of caregiving can affect health related quality of life (HRQOL), the association

\* Corresponding Author: Anita Johansson, RN, PhD, Senior Lecturer, Division of Psychiatry, Skaraborg Hospital, 541 85 Skövde, Sweden.

E-mail addresses: [anita.ulla.johansson@vregion.se](mailto:anita.ulla.johansson@vregion.se) (A. Johansson), [mats.ewertzon@esh.se](mailto:mats.ewertzon@esh.se) (M. Ewertzon), [birgitta.andershed@hig.no](mailto:birgitta.andershed@hig.no) (B. Andershed), [agneta.anderzen-karlsson@orebroll.se](mailto:agneta.anderzen-karlsson@orebroll.se) (A. Anderzen-Carlsson), [salmir.nasic@vregion.se](mailto:salmir.nasic@vregion.se) (S. Nasic), [Arne.Ahlin@stat-inst.se](mailto:Arne.Ahlin@stat-inst.se) (A. Ahlin).

between HRQOL and mood, anxiety, levels of burden and satisfaction with the encounter with professional care, has not been sufficiently investigated. Few studies have been conducted on parental experiences of HRQOL that take gender into account. No studies were identified that specifically describe experiences of the approach of mental health professionals to both mothers and fathers of children suffering from long-term mental disorders.

Therefore, the aim of this study was to investigate a group of mothers and fathers of adult children suffering from long-term mental disorders in Sweden in relation to: (1) their HRQOL compared to Swedish normative data, (2) reported anxiety and depression, burden and experiences of encounters with the psychiatric services and (3) the level of association between the above variables and the participants' HRQOL.

## METHODS

### Design

A cross-sectional study design was performed.

### Subjects and Procedure

Inclusion criteria were parents of an adult child aged 18 years or older, with a history of long-term mental disorder exceeding 2 years and regular contact between parent and child.

Data were collected from October 2012 to May 2013. The participants were recruited in different ways (Fig. 1); through a newspaper advertisement in both rural and urban areas of southern Sweden, followed by on-line advertisements on the Web sites of various Swedish National Organizations and support groups for persons with mental disorders. Finally, an advertisement was published in local newspapers in central Sweden. Respondents who expressed an interest in participating in the study were sent a set of self-report questionnaires, together with an information sheet and a stamped addressed return envelope. One reminder was sent to those who did not respond within 2 to 3 weeks. The study was approved by the Regional Research Ethics Committee in Gothenburg, No. 026-12.

### Data Collection

Socio-demographic data included the parents' age, sex, civil status, ethnic origin, place of residence, frequency of contact with the affected child, membership of a support group and contact with mental health professionals. Data pertaining to the adult children were provided by the parents and included age, sex, time since first contact with the

mental health care service, diagnosis, substance abuse, details of psychiatric care received, e.g. in- or outpatient setting; episodes of compulsory treatment and attempted suicide as known by the parents.

### Questionnaires

Data were collected by means of the following self-report questionnaires:

*The Short Form Health Survey (SF-36®)* is designed to assess HRQOL (Ware & Gandek, 1998). It contains 36 items divided into two parts; (1) The Physical Component Score (PCS) comprising four sub-scales; physical function (PF), role-physical (RP), bodily pain (BP) and general health (GH) and (2) The Mental Component Score (MCS) consisting of four sub-scales; vitality (VT), social function (SF), role-emotional (RE) and mental health (MH). Scores for the eight SF-36 scales range from 0 to 100, with higher scores reflecting better HRQOL. The Swedish version; SF-36v2 and Quality Metric Health Outcomes™ scoring software 4.5 were used in the present study. The reliability and validity of the Swedish version of this instrument have been validated. Normative information on healthy individuals has previously been reported (Sullivan, Karlsson, & Ware, 1995).

The Hospital Anxiety and Depression Scale (HADS) measures the presence of anxiety and depressive symptoms (Zigmond & Snaith, 1983). It contains 14 items divided into two seven-item sub-scales that assess anxiety (HAD-A) and depression (HAD-D) and that can be added to a total score. The score of both sub-scales ranges from 0 to 21, higher scores indicating greater severity. Scores between 8 and 10 are considered a mild, 11 to 14 a moderate and 15 or above a severe level of self-assessed symptoms of anxiety and depression. The HADS has been used extensively in in- and outpatient settings. The reliability and validity have been evaluated in the context of healthcare both internationally and nationally (Bjelland, Dahl, Haug, & Neckelmann, 2002).

The Family Involvement and Alienation Questionnaire (FIAQ) measures family members' experiences of healthcare professionals' approach and feeling of alienation from the provision of professional care (Ewertzon, Lütznén, Svensson, & Andershed, 2008). It contains 28 items divided into two parts; (1) experience of approach, divided into three sub-scales; openness, confirmation and cooperation, and (2) feeling of alienation, divided into two sub-scales; powerlessness and social isolation. The FIAQ response categories contain four alternatives; completely disagree (1), partly disagree (2), partly agree (3) and completely agree (4). A high score for experience of

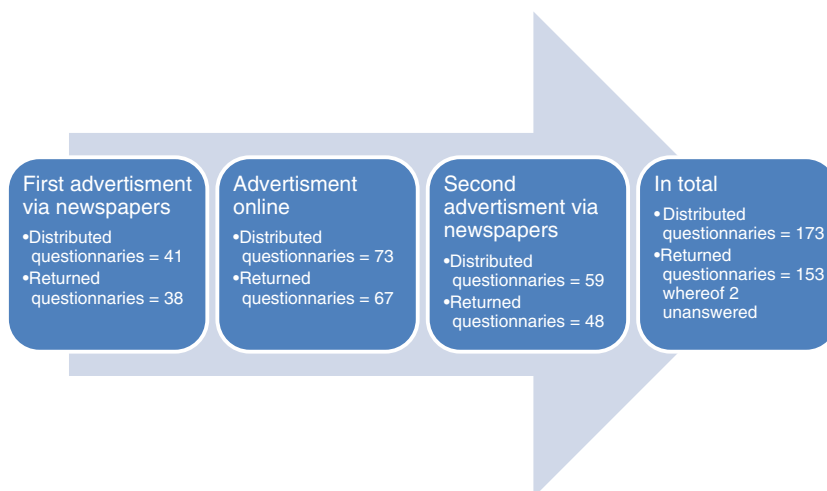


Fig. 1. Overview of distributed questionnaires.

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