

Burden, Health and Sense of Coherence among Relatives of Depressed Inpatients

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Abstract

In Europe, there are an increasing number of persons suffering from depression, which also affects many relatives. The burden and health when being the relative of an inpatient suffering from severe depression has been less examined. The aim of the study was to describe burden, health and sense of coherence among relatives of inpatients with severe depression. Furthermore, the aim was to investigate relatives' burden in relation to their health and sense of coherence. A cross-sectional design was performed, with a questionnaire consisting of background questions and three instruments; Burden Assessment Scale, General Health Questionnaire and Sense of Coherence scale. The participants consisted of 68 relatives recruited from a sample of inpatients diagnosed with depression in the psychiatric specialist health services in one hospital trust in Norway. The Regional Committee for Medical and Health Research Ethics, Norway South East, gave approval to the study. The relatives reported burden to a various degree, with some reporting a significantly greater burden, poorer health and a weaker sense of coherence than others. With regard to subjective burden eight out of ten relatives reported "Worry about future", and almost six out of ten were "Upset by change in patient". Regarding objective burden, more than half the relatives reported having "Less time for friends" and "Reduced leisure time". In conclusion the relatives with a high level of burden reported more mental distress, poorer health and weaker sense of coherence than those with lower level of burden. Further research should focus on identification of factors predicting burden and health of relatives of inpatients with severe depression.

Keywords

Burden, Depression, Health, Inpatients, Relatives

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1. Introduction

Previous research has concluded that relatives of a person with a severe mental illness (e.g. schizophrenia and bipolar disorders) experience burden [1]-[3]. The concept of burden is often operationalized into objective and subjective burden [4], in which objective burden is the observable consequences of the patient's illness, such as financial problems, restrictions on the relatives' leisure activities and on employment. Subjective burden is the psychological consequences for the relatives, such as a feeling of guilt for causing the illness, a feeling of being trapped in the caregiver role and worrying about what the future will bring [5]-[7].

This challenging life situation may influence on the relatives' own health [2] [3] and may influence their ability to manage their caregiver role. In this context, health can be understood as the ability to cope with stress, also known as Salutogenesis. Salutogenesis is strongly connected to sense of coherence (SOC), which is defined as a global attitude that expresses the extent to which a person perceives events or the strains of life as comprehensible, manageable and meaningful [8]. A strong correlation has been reported between weak SOC, high burden and poor mental health [3]. Moreover it is considered that a strong SOC is a coping resource to protect health [9]. SOC may therefore be of importance for relatives' ability to master the consequences of their next of kin's mental illness.

Worldwide, there are an increasing number of people who suffer from depression, which also affects many relatives [10] [11]. The main symptoms of severe depression are lowering of mood, reduction in energy, decrease in activity and reduced capacity for concentration and enjoyment. Reduced self-esteem and self-confidence are often present, as are feelings of guilt or worthlessness [12]. Many patients with depression receive treatment while staying at home, but hospitalization is sometimes inevitable when a major depression seriously interferes with a person's life, and is also one of the primary risk factors for suicide [13].

Qualitative studies have found that relatives of patients with depression experienced a great responsibility for the depressed person, a loss of control in their everyday life, that the relationships in the family are affected and that roles are changed [14]-[16]. The importance of gaining more knowledge about the impact on health and the perceived burden in relatives of patients suffering from depression are highlighted [17]-[19]. Studies with a quantitative design, including this group of relatives with regard to burden and health, have found that relatives experience burden and that their health is affected, but these studies are characterized by small samples [17] [20] [21], and that the relatives were recruited through outpatients clinics [17] or that the depression diagnosis was not defined [19] [22].

As has been shown, studies have reported the consequences of being the relative of a person with a severe mental illness. Being the relative of a person with depression in general is described as being a challenge, and to the best of our knowledge, studies of being the relative of a person suffering from severe depression in need of hospitalization have been scarce. For this reason, the aim of the study was to describe burden, health and sense of coherence with regard to background variables among relatives of inpatients with severe depression. Furthermore, the aim was to investigate relatives' burden in relation to their health and sense of coherence.

2. Method

2.1. Study Design

A cross-sectional design was performed.

2.2. Setting and Participants

The participants consisted of relatives of patients with depression hospitalized in psychiatric specialist health services (PSHS) in one hospital trust in Norway. Six community specialist health centres and three hospitals were included. Nine out of a total of 13 wards which treated patients with depression accepted participation in the study. One health professional at each ward was responsible for the information and recruitment.

The recruitment took place in two stages over a period of 24 months from 2010 to 2012. Firstly, inpatients were asked, both verbally and in writing, for permission to ask one of their closest relative to participate in the study. The inclusion criteria for patients were persons admitted with one of the following diagnoses: Depressive Episodes (F 32.0 - 32.9) and Recurrent Depressive Disorder (F.33.0 - 33.9) in line with the ICD-10 criteria [12], being aged 18 years and older and assessed as having the capacity to give informed consent. The exclusion criteria for patients were bipolar disorders, personality and behavioural disorders, substance abuse and serious so-

matic illnesses and psychotic disorders, with the exception of psychotic depression.

Secondly, relatives were asked both verbally and in writing about participation in the study. The inclusion criteria for relatives were being aged 18 years or older and being able to read and understand Norwegian.

A total of 223 patients with the included depression diagnoses were admitted, and out of these 125 patients were asked for permission to ask one of their relative to participate in the study. Ninety-one patients gave their written consent to ask one close relative to participate. However, 15 relatives declined to participate and eight relatives who had given their written consent did not return the questionnaire. In total, 68 (response rate 75%) relatives participated in the study, 35 (51.5%) were recruited from hospital wards and 33 (48.5%) from community specialist health centers.

2.3. Data Collection

2.3.1. Procedure

The health professional responsible for the recruitment distributed the questionnaire to the relatives. The participant returned completed the questionnaire by post to the first author. One reminder was sent.

2.3.2. Questionnaire

The questionnaire consisted of three instruments that measured the relatives' burden, mental health and sense of coherence. In addition, seven background questions (see [Table 1](#)) and two global health questions were asked.

The burden was measured with the Burden Assessment Scale (BAS) [5], which consists of 19 items in five dimensions representing: Disrupted Activities, Personal Distress, Time Perspective, Guilt and Basic Social Functioning. The objective burden consists of the Disrupted Activities and Basic Social Functioning dimensions, whereas the dimensions Personal Distress, Time Perspective and Guilt constitute the subjective burden. The response options ranged from 1 (Not at all) to 4 (A lot), and each item had the alternative of "Not applicable". A sum score was calculated for the total burden, ranging from 19 (no burden) to 76 (a lot of burden). The instrument has been tested for validity and reliability [5] [6]. The Cronbach's alpha coefficient in this study was 0.88. The BAS scale was translated into Norwegian inspired by Yu *et al.*'s [23] description of back translation. The Norwegian version of the instrument was tested for both face and content validity [24] by ten health professionals, but no revisions were suggested.

Participants with up to five "Not applicable" were included when calculating the BAS total score. Not applicable marks were treated as missing items. These items were replaced by each respondent's mean score, *i.e.* the case means substitution technique [25]. One participant was excluded due to a high number of not applicable marks. In total, 67 participants were included in the BAS.

Relatives' mental health was measured with the General Health Questionnaire, GHQ-12 [26]. On each of the 12 items, the person was asked whether he or she had experienced mental distress over the past two weeks (e.g. lost sleep over worry, been able to face problems). For each question, four response options were provided: "Less than usual", "As usual", "More than usual" and "Much more than usual". In this study, the 0-0-1-1 was used for calculating the GHQ total score [27] [28], ranging between 0 and 12. Persons marking 4 or more are considered as having a significant experience of mental distress [26] [29]. The instrument has been tested for validity and reliability [27] [29] [30], and the Cronbach's alpha coefficient in this study was 0.92.

The Sense of Coherence scale (SOC) developed by Antonovsky [31] was used to measure to what extent the relatives found life manageable, comprehensible and meaningful. In this study the short version with 13 items was chosen [32]. The items have a seven-point response scale with the anchors defined, with the total score ranging from 13 (weaker SOC) to 91 (stronger SOC). The instrument has been tested for validity and reliability [33] [34], and the Cronbach's alpha coefficient in the present study was 0.88.

In addition, there were questions about the relatives' background including sex, age, whether they had children under the age of 18, marital status, education, relationship with the depressed person, and whether they were living together or not with the person suffering from depression. Lastly, two global questions were used concerning perceived health and well-being: "How do you consider your physical health right now?" and "How do you consider your mental well-being right now?" each with a five-point response scale ranging from 1 (Very bad) to 5 (Very good).

2.4. Statistical Analysis

Statistical analysis was performed using the SPSS version 20. Descriptive statistics with frequency, mean and

standard deviation were used. A Cronbach's alpha coefficient was calculated to assess the internal consistency of the instruments. Non-parametric tests were found to be appropriate since the data were ordinal and because of substantial differences in the group sizes in terms of some background variables [35]. The significance level was set to $p < 0.05$ (two-tailed).

With regard to BAS, GHQ and SOC, Mann-Whitney *U*-test [36] was used to compare for differences between two groups (sex, marital status, if they had children under the age of 18 or not and whether they lived together or not with the person suffering from depression) and Kruskal-Wallis test [36] was used to compare three groups (age groups, level of education and the relative's relationship with the depressed person). The relatives were divided into three groups according to the total BAS score: group A (≤ 37), group B ($>37 - \leq 47$) and group C (>47). Kruskal-Wallis test was used to compare the three groups with regard to GHQ, SOC, physical health and mental well-being. When a statistical difference between the three groups appeared Mann-Whitney *U*-test was used for pair wise comparisons. Due to multiple comparisons the Bonferroni adjustment was used to protect against Type I error [36]. A stronger level of significance, $p < 0.0167$, was chosen.

2.5. Ethical Considerations

Ethical considerations were made regarding integrity, confidentiality and the voluntariness of the participants [37]. The Regional Committee for Medical and Health Research Ethics, Norway (South East) approved the study (ref. 2010/126).

3. Results

Of the 68 participating relatives, there was a predominance of women. The majority of the relatives were between the ages of 41 - 59, most were married or cohabiting and half the relatives had upper secondary school. According to their relationship with the depressed person, nearly half were adult children. In addition, less than half of the relatives lived together with the depressed person (Table 1).

The relatives' background in relation to the mean scores of BAS, GHQ and SOC is described in Table 1. Males reported lower burden and mental distress, as well as stronger sense of coherence, than females. With regard to age groups, relatives between the ages of 40 and 59 reported the strongest sense of coherence. Considering educational level, relatives with upper secondary school reported the lowest burden and strongest sense of coherence; whereas those with compulsory comprehensive school reported highest level of mental distress and weakest sense of coherence. With respect to their relationship with the depressed person, adult children had highest burden, while spouses/cohabitants reported highest mental distress. Relatives who did not live together with the person suffering from depression reported highest burden, whereas those who lived together reported highest level of mental distress. No significant differences between the relatives' background and their burden, sense of coherence and mental distress were found.

Table 1. Relatives' background in relation to total burden (BAS), mental health (GHQ) and sense of coherence (SOC).

		BAS ¹	GHQ ²	SOC ³
	N (%)	n = 67 Mean (SD)	n = 68 Mean (SD)	n = 68 Mean (SD)
Total score		43.34 (11.16)	4.77 (4.18)	63.91 (13.34)
Sex				
Male	27 (40)	42.73 (11.71)	4.11 (4.08)	65.18 (9.96)
Female	40 (60)	43.75 (10.91)	5.21 (4.23)	63.07 (15.23)
Age				
18 - 39	11 (16)	43.63 (8.67)	4.00 (3.49)	60.63 (12.29)
40 - 59	43 (63)	43.28 (11.69)	4.93 (4.30)	65.46 (11.12)
60 - 81	14 (21)	43.27 (11.98)	4.92 (4.53)	61.71 (19.49)
Children under 18 years				
Yes	16 (24)	44.50 (13.46)	4.18 (4.35)	64.43 (12.89)
No	50 (76)	42.97 (10.46)	4.96 (4.15)	63.75 (13.60)

Continued

Marital status				
Married/cohabitant	54 (79)	43.23 (11.14)	4.75 (4.15)	63.85 (13.60)
Divorced/single/widowed	14 (21)	43.80 (11.68)	4.85 (4.46)	64.14 (12.76)
Education				
Compulsory comprehensive school	11 (16)	44.07 (8.71)	6.00 (4.65)	56.58 (20.25)
Upper secondary school	33 (50)	41.44 (10.20)	4.32 (3.98)	66.38 (11.19)
University	22 (34)	45.78 (13.44)	4.81 (4.29)	64.09 (10.77)
Relationship with the depressed person				
Spouse/cohabitant	25 (38)	41.73 (10.57)	5.34 (4.13)	63.46 (14.90)
Children	31 (47)	45.10 (11.81)	4.54 (4.09)	62.83 (11.89)
Other (e.g. parents, siblings)	10 (15)	42.06 (10.87)	4.09 (4.76)	68.00 (13.82)
Living together with the person suffering from depression				
Yes	27 (40)	41.19 (11.81)	5.11 (4.19)	63.07 (14.61)
No	39 (57)	45.01 (10.81)	4.41 (4.25)	64.69 (12.59)

¹Burden Assessment Scale. Sum score ranged from 19 (no burden) to 76 (a lot of burden). ²General Health Questionnaire. Sum score ranged between 0 (most favourable) and 12 (least favourable). ³Sense of Coherence scale. Sum score ranged from 13 (weaker) to 91 (stronger).

The number and percentage of relatives who reported “Some” or “A lot” of burden at item level are listed in **Table 2**. The four items most frequently reported were: “Worry about future” (82%), “Upset by change in patient” (58%), “Less time for friends” (55%) and “Reduced leisure time” (54%). The least frequently reported burden was: “Guilty for causing illness” (10%), “Financial problems” (12%), “Friend frictions” (13%) and “Embarrassed by patient” (16%).

The relatives were divided into three groups with respect to the total mean score of BAS. The three groups were compared for differences concerning GHQ, SOC, physical health and mental well-being, and there were significant differences between the groups. Significant differences were noted between relatives in group A and relatives in group C, with the relatives in group C reporting higher burden, more mental distress, weaker sense of coherence, and poorer physical health and mental well-being. Furthermore, the relatives in group C reported weaker sense of coherence than group B (**Table 3**).

Table 2. Burden Assessment Scale (BAS) items, frequencies and percentages of “Some” and “A lot” responses.

Items	n	%
Worry about future ¹	55	82
Upset by change in patient ¹	39	58
Less time for friends ²	37	55
Reduced leisure time ²	36	54
Guilty in not helping enough ¹	33	49
Upset household routine ²	33	49
Difficulty concentrating ²	33	49
Felt trapped ²	31	46
Changed personal plans ²	31	46
Neglected family's needs ²	30	45
Stigma upsetting ¹	27	40
Family frictions ¹	25	37
Resented demands ¹	24	36
Worry about making illness worse ¹	22	33
Missed work/school ²	19	28
Embarrassed by patient ¹	11	16
Friend frictions ²	9	13
Financial problems ²	8	12
Guilty for causing illness ¹	7	10

¹Subjective burden; ²Objective burden.

Table 3. Three groups of burden (A, B, C) compared with regard to GHQ, SOC, physical health and mental well-being.

	Group A BAS $\leq 37^1$ n = 23	Group B BAS > 37 - $\leq 47^1$ n = 22	Group C BAS > 47 ¹ n = 22	Kruskal-Wallis test		Mann Whitney U-test ²		
	Mean (SD)	Mean (SD)	Mean (SD)	χ^2	p	A-B	A-C	B-C
GHQ ³	2.47 (3.21)	5.18 (4.05)	7.00 (4.04)	12.86	0.002	0.034	0.000	0.117
SOC ⁴	68.69 (9.40)	66.45 (12.13)	55.31 (13.92)	13.31	0.001	0.609	0.001	0.005
Physical health ⁵	4.04 (0.82)	3.77 (0.75)	3.27 (0.82)	11.13	0.004	0.147	0.002	0.030
Mental well-being ⁵	4.13 (0.69)	3.59 (0.85)	3.27 (0.98)	10.02	0.007	0.031	0.002	0.291

¹Burden Assessment Scale (BAS). Sum score ranged from 19 (no burden) to 76 (a lot of burden). ²Post hoc test between pair of groups, showing p-values. ³General Health Questionnaire. Sum score ranged between 0 (most favourable) and 12 (least favourable). ⁴Sense of Coherence scale. Sum score ranged from 13 (weaker) to 91 (stronger). ⁵Physical health and Mental well-being; response scale ranging from 1 (Very bad) to 5 (Very good).

4. Discussion

The aim of the study was to describe burden, health and sense of coherence with regard to background variables among relatives of inpatients with severe depression and to investigate relatives' burden in relation to their health and sense of coherence. This study revealed variations between relatives, with some reporting a greater burden, poorer health and a weaker sense of coherence than others.

The severity of the symptoms is often reported as the factor that places the greatest burden on the relatives of persons with severe mental illness [38]. In this study the patients were hospitalized because of depression, which indicates that the symptoms were severe; otherwise an outpatient treatment would have been given. Van Wijngaarden *et al.* [39] found few differences between the relatives of depressed outpatients and the relatives of persons with schizophrenia. Hence, the relatives of depressed persons more often experienced a strained atmosphere. Compared to the relatives of outpatients diagnosed with depression, the relatives of inpatients reported more extreme tiredness, sleeplessness and a lack of appetite [20]. With regard to subjective burden eight out of ten relatives reported "Worry about future", and almost six out of ten were "Upset by change in patient". This is supported by other studies of relatives to mentally ill persons with schizophrenia [40] [41] and dementia [42]. What the relatives worry about concerning the future may be dependent on their relationship to the patients [43].

Regarding objective burden, more than half the relatives reported having "Less time for friends" and "Reduced leisure time" more frequently compared to another study of relatives of patients with severe mental illness [43]. Relatives who did not live in the same household as the person suffering from depression reported higher burden than those relatives who shared the household. Not living together with the person suffering from depression could require planning in terms of taking care of the person, and relatives might also worry about what happened to the person when they were apart. The adult children were most represented in this group and they may have their own family to take care of, in addition to the depressed parent, which may reduce their amount of leisure time.

Almost half of the relatives in the present study were adult children of the depressed person, and they reported the highest burden. Children, including the adult children of a parent with depression, face a demanding situation and the experience of being controlled by their parents and unable to live the life they wanted [16]. Hedman Ahlström *et al.* [44] reported that anxiety and concerns for the depressed parent affected children, even after they moved out. Changes in the depressed person from prior to the onset of depression often affect the interpersonal relationships and changed the roles in the family. The relatives may also worry about that their next of kin could commit suicide [16].

The relatives' "Worry about future" and being "Upset by change in patient" may be attributed to the lack of knowledge about depression and what they can expect from treatment and the course of treatment. Knowledge about depression is of importance when relatives are attempting to understand and engage with the depressed next of kin in an appropriate manner [16]. Gaining more knowledge about what the relatives can expect concerning the diagnosis and the course of treatment could help to make the future more predictable. The nurses play an important role in this, supporting the relatives in finding the best ways to meet the challenge and create meaning in this situation.

Some of the relatives in this study reported poorer health than university students in a Norwegian study [29] and a population sample in a Swedish study [34]. Almost four out of ten relatives were spouses/cohabitants of the

depressed person reported a high GHQ mean score. A Norwegian population study [19] reported significantly higher levels of symptoms of depression and anxiety and a lower degree of subjective well-being among spouses of persons suffering from anxiety and depression disorders compared to spouses to persons not suffering from these mental disorders. Depression is found to influence communication between spouses in a negative manner [45] and to provide care for the depressed spouse in addition to holding down a job and taking care of other family members may be a challenge [16].

Sense of coherence is found to be a resource with an impact on how people deal with stressful life events and how they mobilize their resources in a health-promoting manner [46]. The SOC mean score among the relatives in this study is somewhat higher than in a Norwegian sample of relatives of persons with severe mental illnesses [3]. On the other hand the relatives in the present study showed a weaker SOC compared to a Swedish population study [34]. Critical life events may decrease the level of SOC [47] and a weak SOC represents a health risk, while a stronger SOC is related to better health [46]. Antonovsky [8] describes General Resistance Resources (GRR), e.g. social networks, social support, self-esteem, healthy behaviour and knowledge, all of which are factors of importance when handling difficult life situations. GRR may help the relatives to handle the situation.

Nurses have a responsibility to promote health [48], which requires commitment and a desire to try to understand the uniqueness in the situation of the relative. When this study revealed that relatives differ in their extent of perceived burden, there is probably no single intervention that could address this heterogeneity. When nurses have knowledge about which factors are of importance to help cope with demanding life situations, they may be able to identify relatives at risk of developing their own health problems.

Methodological and Ethical Considerations

The present study has both strengths and limitations that have to be noted. One strength is the clear inclusion criteria with reference to the relatives of inpatients and a further diagnosis of depression according to ICD-10. This stands in contrast to other quantitative studies, which primarily refer to the relatives of patients with depressive disorders/depression in general [19] [22].

The response rate in this study was 75% which may be seen as a strength [24]. The first author visited all the wards in order to provide information about the study and have regular contact by phone and e-mail with the health personnel recruited to remind them and to answer any questions concerning the recruitment.

During the recruitment period, a total of 223 patients were admitted with depression diagnoses; of these, 125 patients were asked for permission to ask one of their relatives to participate in the study. Those patients may have been excluded because of not having the capacity to give informed consent, having relatives under the age of 18 and/or not being able to speak and understand Norwegian. Another reason for exclusion was when patients only had formal caregivers or had conflictual relationships. The data collection was carried out over a 24-month period from 2010 to 2012. Two festive seasons and two summers are included in the data collection period, and some patients may have been overlooked or been forgotten to be asked because of periods with temporary staff. The sample size was relatively small and was recruited from only one hospital trust in Norway; therefore, generalizability must be interpreted with caution.

The recruitment procedure was comprehensive in that the patients were asked for permission to ask their closest relatives to participate in this study, which was a requirement from the Regional Committee for Medical and Health Research Ethics. Furthermore, no information about the patients was allowed. Lack of information about the patients' symptoms and the duration of the depression may be seen as a limitation. However, what we know is that the depression was serious enough to require hospitalization.

Both the SOC and GHQ instruments are well known and frequently tested for validity and reliability in multiple samples. The Cronbach's alpha coefficients in the present study showed a good reliability concerning SOC, GHQ and BAS. The BAS was chosen because it measures both objective and subjective burden. The Norwegian version of BAS was pilot tested by a panel of researchers in mental health.

5. Conclusion

The relatives of inpatients with severe depression reported burden to a various degree. Subjective burden was more frequently reported than objective burden. The relatives with higher level of burden reported more mental distress, poorer health and weaker sense of coherence than those with a lower level of burden. Further research should focus on identification of factors predicting burden and health of relatives of inpatients with severe de-

pression. There is also a need to investigate the relatives' experiences of support from the psychiatric specialist health services.

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