

“How Much Can I Take?”: Predictors of Perceived Burden for Relatives of People with Chronic Illness

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Abstract

Introduction: Chronic illnesses are common and have detrimental effects not only on the affected individuals but also on their families. These negative consequences on the physical and psychological health of caregivers constitute the burden of care. We investigate the predictors of perceived burden of care among relatives of people with any chronic physical or mental illness using secondary data from a nationwide survey in Singapore. **Materials and Methods:** A cross-sectional household survey was conducted among adult residents of age 18 years and above and data were analysed to explore the predictors of high perceived burden of care. Two thousand four hundred and fifty-eight respondents having at least 1 close relative with any chronic physical and/or mental illness were included. **Results:** Majority of the respondents had at least 1 close family member with physical illness (88.3%)—the most common illnesses reported were memory problems (86.9%), physical disability (74.8%), heart problems (70.1%) and cancer (62.2%). About 30.9% (n = 723) perceived high burden resulting from their relatives' health condition. Logistic analysis showed that women were more likely (OR 1.58, $P = 0.0026$) and Malays were less likely (OR 0.68, $P = 0.0044$) to perceive burden. Those who were able to open up to their family or friends (OR 1.65, $P = 0.0162$) and those who had dysthymia had higher odds (OR 4.91, respectively, $P = 0.0364$) of perceiving burden. **Conclusion:** Our results suggest that regardless of the nature of the chronic illnesses, gender or ethnicity, the capacity to open up to family or friends and the mental health status of caregivers can predict their perceived burden. The results provide valuable preliminary information for planning social policies and interventions for improving the well-being of caregivers.

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Introduction

Having a relative with a chronic illness can be very stressful for the family. A majority of these illnesses are disabling and pose numerous challenges in their management and consequences. The affected individuals often suffer from physical and emotional limitations that interfere with their functioning^{1,2} and capacity to take care of themselves³ and thereby require constant support from family members in their daily activities and finances. This disrupts the usual patterns of interaction,⁴ roles⁵ and leisure⁶ of family members, causing considerable distress and interference in their personal life. A number of studies conducted over the past 2 decades have provided consistent evidence of detrimental effects on physical and psychological health of caregivers of people with chronic illnesses.⁷⁻¹⁰

Burden of care is a complex construct that is usually defined by its impacts and consequences on caregivers.^{11,12} Emotional, psychological, physical and economic impacts of caregiving have been used to define and assess the burden of care.¹³⁻¹⁵ In addition to these, experiences of feelings of guilt, shame, embarrassment, and self-blame in families of people with chronic illnesses have been explored.^{12,16,17} Burden of care has been broadly classified into 2 dimensions—objective and subjective burden.¹⁸ Objective burden of care refers to its physical effect on the household members for the day-to-day tasks they undertake for the person¹⁹ such as the time invested by caregiver and/or family members on helping, supervising, and feeding the ill member. It also includes their experiences of family disturbance and relationship problems, and loss of employment and/

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or leisure as a consequence of the caregiving task.^{20,21} Subjective burden has been defined as the “psychological, social and emotional impact caregivers may experience from the objective burden of care-giving”.²² It indicates the negative psychological influence on the caregivers, such as feelings of guilt, embarrassment, stress and anxiety, and the extent to which they perceive the burden of care.^{23,24} This perception of burden of care and its effect varies across illnesses, individuals and cultures.

Previous research has added to the understanding of the construct of burden of care by investigating several determinants and factors that are likely to contribute to caregiver's perception of the burden of care.^{25,26} Several studies documented the influence of the ill member's age and the symptoms of illness; the age, gender and education level of the caregiver; and social dysfunction experienced by the family.²⁷⁻²⁹ The contribution of ethnicity and cultural issues on subjective burden of care have also been studied.^{30,31} In addition to these, perceived social support is considered as an important predictor of distress in caregivers and cause for burden.³² The loss of social life and leisure activities as the family starts spending more time in caring increase the burden, and has been linked to feelings of embarrassment and shame in relation to certain illnesses.³³ Similarly, there is some evidence supporting that mental status of caregivers is affected by this burden and can in turn influence the burden of care.

While the extant literature has provided strong evidence of the relationship between these determinants and burden of care in the family of the affected person, most studies have focused on burden of individual disorders such as cardiovascular illnesses, cancer, severe mental illnesses, etc. They have not investigated the effect of major chronic illnesses in general in a community sample of family caregivers. Moreover, while most studies have studied depression, anxiety and general mental health as a measure of psychological impact of burden, very few have looked at alcohol use among family caregivers. Studies have also largely neglected the effect of frequency of contact with friends and relatives while assessing the role of social support.

We investigated the effect of demographic, social and health parameters of the family caregiver on their perceived burden of care for any chronic illness using the data collected as part of a nationwide cross-sectional household survey—the Singapore Mental Health Study (SMHS), which investigated the prevalence of psychiatric disorders in Singapore. We explored the relationship of the burden of care with caregivers' chronic physical disorders (based on self-report of any condition ranging from asthma, neurological, cardiovascular disorders, etc) and mental disorders (major depressive, bipolar, generalised anxiety

and obsessive compulsive, dysthymia and alcohol abuse and dependency). We also aimed to study the effect of perceived social support and frequency of contact with family or friends. We hypothesised that there was a positive association of perceived burden with depression and anxiety in the caregivers together with negative influence of perceived social support. We also expected that the frequency of contact with friends or family would be protective towards perception of a lesser burden of care.

Materials and Methods

Ethical Aspects

Ethics approval for the study was obtained from the relevant institutional review and ethics boards. Participation in the survey was voluntary. Written informed consent was obtained from all respondents and guardians/parents for those in the 18 to 20 years of age prior to the interview.

Survey

The detailed survey method is explained in our earlier article.³⁴ In summary, the cross-sectional survey was conducted over a 1-year period between December 2009 and December 2010. Lay interviewers were trained in the administration of instrument using a structured training programme. Computerised and paper-based instruments were interviewer-administered in English, Mandarin or Bahasa Melayu (the 3 predominant languages in Singapore) based on respondents' preference. Robust quality control processes were implemented at various stages of the survey and data management.

Study Sample and Response Rate

Singapore residents (Singapore Citizens and Permanent Residents) aged 18 years and above, belonging to Chinese, Malay, Indian or other ethnic groups, and residing in households across Singapore were included in the SMHS. A list of residents was obtained from an administrative database. Disproportionate stratified sampling strategy was adopted to oversample Malays and Indians, and those aged 65 years and above to establish accurate estimates. Residents who were unable to understand the language of interview or limited by severe physical or mental conditions were excluded from the survey.

Of the 13,500 addresses released to interviewers, respondents were successfully identified at 9116 (67.5%) households. About 4% (396) residents were termed ineligible due to language barrier or incapability to conduct the survey. In all, 6648 (72.9%) respondents participated in the survey, 851 (9.3%) refused, 664 (7.3%) were either away for the entire duration of the survey (535), were not contactable

within maximum contact attempts (84) or were deceased (45) and 554 (6.1%) respondents had permanently moved to another location or country. Of the completed interviews, 32 were rejected due to quality failure. The individual response rate for the study after excluding the ineligible cases was 75.9%.

Of the 6616 respondents, 2458 (37.2%) had at least 1 relative with a chronic illness and these were included in this analysis. Table 1 shows the socio-demographic characteristics of the respondents.

Instruments

The World Mental Health Composite International Diagnostic Interview (CIDI version 3.0)³⁵ was the primary instrument used to determine the diagnosis of mental disorders. The CIDI 3.0 is a structured diagnostic interviewing tool for assessing the lifetime and 12-month prevalence of disorders using the diagnostic criteria from the 2 major psychiatric classification systems—the 10th Edition of the International Classification of Diseases (ICD-10) and the Diagnostic and Statistical Manual, Fourth Edition, of the American Psychiatric Association (DSM-IV). The disease specific modules of CIDI 3.0 employed for the survey were: anxiety disorders (generalised anxiety disorder, obsessive compulsive disorder); mood disorders (major depressive disorder, dysthymia, bipolar disorder); and alcohol abuse disorders (alcohol abuse/dependence). In this study, we found the associations with lifetime mental disorders determined using rules of hierarchy. Additional modules of CIDI 3.0 were used to collect information on social support and burden of caregiving. The computer-assisted personal interviewing (CAPI) mode was used for interviews conducted in English and Mandarin languages. The select modules of CIDI 3.0 were translated into Bahasa Melayu and used in the pen and paper interviewing (PAPI) mode for this language.

CIDI 3.0 Family Burden Module

Respondents were asked how many close and living family members they had (including spouse/partner, parents, siblings and children). They were then presented with a list of 10 chronic physical and mental conditions (Table 2) and for each, were asked to list if any of the above relatives had that health problem. Two open-ended questions also collected information on any other physical or mental condition that were not included in the list. All respondents who reported having at least 1 close relative with any chronic condition were termed as ‘family caregivers’. Their perceived subjective burden relating to the health problems of their relative(s) was captured using a single question, “Taking into consideration your time, energy, emotions,

Table 1. Demographic and Clinical Characteristics of the Sample (n = 2458)

Variables		Unweighted		Weighted	
		Mean	SD	Mean	SE
Age		43.6	13.4	45.8	0.125
		n	%	%	SE
Age Group	18 to 34	673	27.4	23.2	0.0
	35 to 49	1005	40.9	39.7	0.0
	50 to 64	648	26.4	27.2	0.0
	65 and above	132	5.4	9.9	0.0
Ethnicity	Chinese	752	30.6	77.3	0.0
	Malay	834	33.9	11.5	0.0
	Indian	754	30.7	8.3	0.0
	Others	118	4.8	2.9	0.0
Gender	Men	1207	49.1	48.2	1.5
	Women	1251	50.9	51.8	1.5
Marital Status	Never Married	568	23.1	24.5	1.1
	Currently Married	1730	70.4	68.7	1.3
	Divorced/Separated	158	6.4	6.8	0.8
Education	Pre-primary	101	4.1	4.8	0.7
	Primary	366	14.9	15.4	1.1
	Secondary	765	31.1	28.6	1.3
	Pre-u/Junior College/Diploma	472	19.2	20.4	1.1
	Vocational	241	9.8	7.1	0.7
	University	513	20.9	23.7	1.2
Employment	Employed	1720	72.1	71.0	1.2
	Economically inactive*	548	23.0	24.4	1.2
	Unemployed	117	4.9	4.6	0.6
Personal Income	Below S\$20,000	1207	51.4	47.3	1.4
	S\$20,000 to 49,999	730	31.1	32.2	1.3
	S\$50,000 and above	412	17.5	20.6	1.2
Lifetime Mental Disorders	Major Depressive Disorder	183	7.5	6.7	0.7
	Dysthymia	13	0.5	0.3	0.1
	Bipolar Disorder	44	1.8	1.7	0.4
	Generalised Anxiety Disorder	45	2.4	1.4	0.3
	Obsessive Compulsive Disorder	101	4.1	4.0	0.5
	Alcohol Abuse	94	3.8	3.7	0.5
	Alcohol Dependence	21	0.9	0.5	0.1
	Any mental disorder	388	15.8	14.5	1.0
	Any chronic physical condition	1198	48.7	48.4	1.4

*includes homemakers, students and retirees/pensioners

Table 2. Distribution of Respondents Having Family Member(s) with Chronic Illnesses

	Total			Parents		Siblings		Children		Spouse	
	n	%	SE	%	SE	%	SE	%	SE	%	SE
Relative has..											
Physical and/or Mental illness	2458	100.0	0.0	62.2	1.2	40.4	1.4	4.1	0.6	11.1	0.9
Any Physical illness	2151	88.3	0.9	65.5	1.3	38.4	1.5	3.4	0.6	11.4	1.0
Any Mental illness	605	24.3	1.2	55.3	2.5	59.4	2.8	8.0	1.6	12.2	1.9
Type of Physical illnesses											
Cancer	396	20.4	1.2	62.2	2.9	43.5	3.1	5.6	1.7	15.8	2.5
Heart problem	670	21.6	1.2	70.1	2.1	41.6	2.7	1.2	0.3	9.8	1.8
Memory problem	205	10.3	0.9	86.9	3.3	36.8	4.6	0.8	0.4	5.4	2.4
Mental Retardation	117	6.4	0.8	41.9	6.3	71.6	5.9	6.6	3.2	12.3	4.3
Physical Disability	125	4.7	0.6	74.8	5.2	38.9	5.9	5.8	3.1	6.6	3.2
Other Physical illness	1274	50.4	1.5	71.5	1.6	37.4	1.9	2.7	0.7	11.2	1.3
Type of Mental illnesses											
Depression	315	12.6	0.9	55.7	3.6	61.9	3.8	8.0	1.6	13.3	2.6
Anxiety	224	10.5	0.9	60.4	3.7	55.9	4.5	10.4	3.0	12.8	2.9
Psychosis	73	3.6	0.6	35.8	6.4	70.3	5.6	14.2	2.8	10.5	4.7
Manic Depression	37	1.6	0.4	36.2	10.7	77.0	1.9	12.6	0.0	1.4	0.8
Alcohol/Drug Use	178	5.1	0.6	53.0	5.0	65.5	6.0	8.5	4.0	7.7	3.9
Other Mental Problem	35	2.1	0.4	44.6	9.5	66.9	9.2	24.2	7.6	15.2	7.6

finances and daily activities, would you say that [his/her/their] health problems effect your life a lot, some, a little or not at all?" Two additional indicators of subjective burden were assessed from responses to how much the relative(s) illness caused the respondent (1) embarrassment and (2) to be worried, anxious or depressed using 4-point scale where '1' denoted 'A lot' and 4 'Not at all'. A minimum response of 'some' (which was response option '2') was classified as high perceived burden.

Two parameters of objective burden were measured: (1) Whether respondents spent time on top of their usual routine in doing things for the relative(s), which was computed from 4 questions which addressed whether respondents spent time in helping with activities like washing, dressing, paper work, getting around, taking medications, giving emotional support, etc.; and (2) financial cost to respondent because of the relative(s) illness either in terms of money spent or earnings lost.

CIDI 3.0 Social Network Module

Data on whether the respondent had supportive relationships with friends and relatives not residing with them was collected in this section. Perceived social support was determined from 2 questions: "How much can you rely on your [friends/relatives who do not live with you] for help if you have a serious problem?" and "How much can you open up to your [friend/relative not living with you]

if you have a serious problem?" where respondents were asked to choose from a 4-point scale with '1' being 'A lot' and 4 'Not at all'. The scale was dichotomised and poor support was computed for 2 domains of perceived social support ('rely on' and 'open up') if the respondents selected 'a little' or 'not at all' (Options 3 or 4) as their answer to these questions. The PAPI version of the CIDI 3.0 (used for interviews in Bahasa Melayu language) combines the information on friends and relatives into a single question. Hence, the CAPI data was combined for the 2 questions i.e. poor perceived social support was computed as 'yes' if the respondent endorsed options 3 or 4 ('a little' or 'not at all') for either friend or relative for each domain. The frequency of contact with friends and relatives and how often they confided in someone when they had a problem or worry was also collected.

Other Instruments

Besides the CIDI 3.0, respondents were also asked information on their socio-demographic background and history of chronic physical illnesses using a PAPI questionnaire.

Statistical Analyses

Statistical analyses were carried out using the Statistical Analysis Software (SAS) System version 9.2 (SAS Institute,

Cary, NC). Data were weighted back to population to adjust for oversampling and post-stratification by age and ethnicity. Descriptive analyses were performed to establish the socio-demographic characteristics, prevalence of lifetime mental disorder as well as to describe the perceived burden and social-support profile of the study population. Associations between perceived burden and socio-demographic variables, lifetime mental disorders, social support profile were examined using bivariate and multivariate logistic regression. Standard errors (SE) and significance tests were estimated using the Taylor series' linearisation method to adjust for the weighting. Chi-square (χ^2) tests were used for bivariate analysis. Multivariate significance was evaluated using Wald χ^2 tests based on design corrected coefficient variance-covariance matrices. Statistical significance was set at $P < 0.05$ using two-sided tests. Parameters of objective and subjective burden were not included in the bivariate and multivariate analysis as the respondents who did not perceive burden did not answer these questions because of the skip logic of the CIDI 3.0.

Results

Socio-demographic and Clinical Characteristics of the Sample

The socio-demographic and clinical characteristic distribution of overall sample is presented in Table 1. The study sample comprised 2458 respondents with a mean (SD) age of 45.8 (13.4) years, range between 18 and 88 years. Majority of the samples were Chinese (77.3%), followed by Malays (11.5%), Indians (8.3%) and 2.9% belonged to other ethnic groups. Of the respondents, 51.8% were women. Majority of the samples were employed (71%). The lifetime prevalence of any mental disorders and any chronic medical condition was 14.5% and 48.4%, respectively. Major depressive disorder was the commonest (6.7%) mental illness. Most of the respondents had reported that they relied on their family or friends if they had a serious problem (68.5%) and would, in such circumstances, open up about their worries with family or friends (70.1%). There were 30.9% respondents who perceived high burden due to chronic health problems of their close family members. Table 2 shows the distribution and proportion of chronic health problems among respondents' close family members. Majority of the respondents had at least one close family member with physical illness (88.3%). Having a parent with chronic health problems such as memory problem (86.9%), physical disability (74.8%), heart problem (70.1%) and cancer (62.2%) was the most common occurrence among the respondents.

Factor Associated with High Perceived Burden

Table 3 reports the factors associated with high perceived burden among those who had at least 1 close family member with a chronic health problem. Age, gender, ethnicity, marital status, education, income, "being able to open up", having dysthymia, major depressive, bipolar, generalised anxiety or obsessive compulsive disorder were significantly and independently associated with high perceived burden. However, effect of some parameters did not remain significant upon multivariate investigation. Ethnicity remained a predictor. As compared to the Chinese, Malays had lower odds of perceived burden. Women were more likely than men to perceive higher burden (34.4% vs 27.1%, OR = 1.58, $P = 0.0026$). Respondents who could open up about their worries to family or friends and those having dysthymia had higher odds of perceived burden. The model explained about 10% variance in this population ($R^2 = 9.95$).

Objective and Subjective Burden

Table 4 presents the proportion of respondents with objective and subjective burden among those who reported perceived burden. More respondents having a relative with physical illness reported objective burden in terms of time spent in caring and associated costs, while more respondents with a mentally ill relative experienced feelings of embarrassment and worry.

Discussion

Our findings are consistent with other studies despite the differences in the definition of perceived burden. Although different illnesses have their own symptoms and demands on the caregiver, gender and ethnicity emerge as strong predictors of burden, with men and those belonging to Malay ethnicity being less likely to perceive burden. High burden among female caregivers has been widely reported in earlier studies.^{36,37} A study conducted among Malay caregivers of patients with schizophrenia reported that despite their burden, Malays were less likely to complain about it.³⁸ This could be a reason for the low expressed and perceived burden among this group.

We expected to find positive association of perceived burden of care with anxiety and depression. Caregiver anxiety often results in feelings of fear of the unknown, and worry about their relatives' health and future; and these have been more strongly associated with the subjective aspects of burden.³⁹ However, we did not find any association of perceived burden with generalised anxiety disorders or depression, a finding that has been widely hypothesised and repeatedly documented in the literature.⁴⁰⁻⁴³ There could be several reasons to this. Very few studies have

Table 3. Predictors of Perceived Burden for Respondents Having a Relative with a Chronic Illness

Table 5: Predictors of Perceived Burden for Respondents Having a Relative with a Chronic Illness									
Variables		Bivariate analysis				Multivariate analysis			
		n	With perceived burden	Without perceived burden	P value*	OR†	95% CI		P value
		2458	%	%					
Age group	18 to 34	673	35.1	64.9	0.0003	1.00			
	35 to 49	1005	36.1	63.9		1.38	0.95	2.00	0.0944
	50 to 64	648	24.2	75.8		0.91	0.58	1.44	0.6927
	65 and above	132	18.5	81.5		1.04	0.45	2.40	0.9283
Ethnicity	Chinese	752	31.8	68.2	0.0157	1.00			
	Malay	834	24.7	75.3		0.68	0.52	0.89	0.0044
	Indian	754	30.6	69.4		0.90	0.70	1.16	0.4062
	Others	118	31.6	68.4		0.97	0.58	1.61	0.9040
Gender	Men	1207	27.1	72.9	0.0072	1.00			
	Women	1251	34.4	65.6		1.58	1.17	2.14	0.0026
Marital Status	Never Married	568	35.8	64.2	0.0212	1.00			
	Currently Married	1730	30.2	69.8		0.77	0.54	1.09	0.1390
	Divorced/Separated/ Widowed	158	19.9	80.1		0.53	0.26	1.09	0.0829
Education	Pre-primary	101	12.5	87.5	0.0003	0.48	0.16	1.43	0.1889
	Primary	366	20.2	79.8		0.68	0.37	1.22	0.1934
	Secondary	765	31.3	68.7		0.95	0.61	1.49	0.8300
	Pre-u/Junior College/Diploma	472	35.0	65.0		0.97	0.64	1.46	0.8762
	Vocational	241	37.7	62.3		1.45	0.83	2.52	0.1881
	University	513	35.5	64.5		1.00			
Employment	Employed	1720	32.9	67.1	0.0747	1.00			
	Economically Inactive	548	25.3	74.7		0.92	0.60	1.40	0.6886
	Unemployed	117	29.5	70.5		0.87	0.42	1.81	0.7148
Income	Below S\$20,000	1207	26.3	73.7	0.0013	0.90	0.55	1.45	0.6532
	S\$20,000 to 49,999	730	37.8	62.2		1.32	0.87	2.01	0.1867
	S\$50,000 and above	412	32.5	67.5		1.00			
Social support									
	Rely on Relatives/Friends	1745	32.7	67.3	0.0549	0.79	0.54	1.16	0.2256
	Open up to Relatives/Friends	1746	34.7	65.3	<0.0001	1.65	1.10	2.48	0.0162
	Poor interaction with Relatives/Friends	1186	30.5	69.5	0.7451	1.09	0.82	1.44	0.5558
Health									
	Major Depressive Disorder	183	44.3	55.7	0.0059	1.63	0.97	2.73	0.0661
	Dysthymia	13	82.0	18.0	<0.0001	4.91	1.11	21.77	0.0364
	Bipolar Disorder	44	55.0	45.0	0.014	2.02	0.87	4.68	0.1023
	Generalised Anxiety Disorder	45	58.0	42.0	0.0096	1.59	0.65	3.93	0.3133
	Obsessive Compulsive Disorder	101	46.7	53.3	0.013	1.66	0.91	3.04	0.0993
	Alcohol Abuse	94	34.5	65.5	0.3024	1.08	0.54	2.13	0.8337
	Alcohol Dependence	21	40.4	59.6	0.4276	0.92	0.21	4.09	0.9100
	Any chronic physical condition	1198	29.9	70.1	0.4972	1.11	0.84	1.47	0.4677

*chi-square tests

†OR based on multiple logistic regression model. Significance was set at $P < 0.05$

Table 4. Objective and Subjective Burden Among Respondents Who Perceived Burden of Care (n = 723)

Relatives with...		Any chronic illness (n = 723)		Any chronic mental illness (n = 240)		Any chronic physical illness (n = 603)	
		n	%	n	%	n	%
Objective burden	Time spent on ..						
	Physical tasks (cleaning, feeding, giving medicines, etc.)	357	44.7	99	34.8	329	48.9
	Providing emotional support	482	69.3	141	62.5	422	69.9
	General tasks for the relative on top of what caregiver usually does	567	79.1	176	75.3	493	79.4
	Financial cost (Paying for relative/earnings lost)	318	42.5	94	34.6	289	46.2
Subjective burden	Feelings of ..						
	Embarrassment	73	7.0	45	13.0	51	6.0
	Being Worried/anxious/depressed	431	57.3	160	67.9	368	56.3

used detailed structured instruments such as the CIDI 3.0 to establish a diagnosis of depression resulting in possible differences in the assessment of depression. Likewise, because we included only those respondents who met the DSM-IV diagnosis of major depressive disorder, we might have excluded those who had sub-threshold depressive disorder and symptoms. It is noteworthy that dysthymia remained significant after regression analysis suggesting that milder forms of depression may have been prevalent in this population. However, we did observe a strong association of depression and generalised anxiety disorders at bivariate level ($P < 0.001$) similar to other studies.⁴⁴ Our attempt at exploring the relationship of alcohol use with perceived burden did not yield any predictive findings contrary to the studies elsewhere.^{45,46} It could be due to some cultural differences in coping with stress, with perhaps a lesser predilection among our local population resorting to alcohol although further work in this area is needed to understand the role of alcohol use in care burden.

Another interesting finding that went against our hypothesis was the effect of the domain of perceived social support i.e. being able to open up to someone would be positively associated with perceived burden. Family members who are able to draw upon emotional support from others have been known to have greater well-being and less burden⁴⁷ suggesting that increase in social support could reduce the psychological distress of care. We did not observe significant association of other domains of

perceived social support, i.e. being able to rely on family or friends and the frequency of contact. This finding suggests that domains of social support may operate differently in different settings and cultures and more understanding of the social interaction patterns in the Singapore community is needed to establish its relation to burden of care.

Although objective and subjective aspects of burden could not be statistically explored in this study, descriptive analysis showed that a similar proportion of caregivers experienced objective burden irrespective of whether the relative had a physical or mental illness. However, a higher proportion of people perceived subjective burden among those having a mentally ill relative. Similar findings have been reported in earlier studies⁴⁸ and this effect has been attributed to the differences in symptoms of the illnesses such as perceived aggression, lack of self-care and grooming and weight gain⁴⁹ and associated stigma.⁵⁰

Limitations and Strengths of the Study

While the study has provided confirmation and better understanding of the determinants of burden in caregivers, the findings should be regarded as a preliminary exploratory study of the role of caregivers' social support and mental health on their perceived burden. The study is limited by our choice of a cross-sectional study design that did not allow for establishing the temporal sequence of events and hence, derive causal inferences. There was also a 24.1% non-response which might have introduced some bias in the findings. The information on relatives' health status was collected by respondents' self-report which may be prone to reporting and recall bias. We could not confirm the information on the health status of the family member from other sources such as interviewing another family member or using administrative databases. The definition of 'family caregiver' was broad and was not exclusive as for 'primary caregiver'. It is possible that primary caregiver would experience higher burden than other family caregivers⁵¹ and this was not investigated here. It was also not possible to determine if burden was associated with the severity of relatives' illness—a perspective that has generated conflicting findings.⁵² In our study, only one aspect of perceived social support—the capacity to open up, predicted burden. However, the construct of social support assessed by us was limited to support (rely on, open up, interact often with) from family or friends as we did not include support from caregivers' spouse or partner. Influence of support arising from participation in religious groups has also been reported as another source of respite from the social isolation,⁵³ which was not investigated in our study. The predictors explained only 10% variance in the sample. We attribute this to the lack of information on other important factors related to family burden such

as being a primary caregiver, time spent on caring for the individual, number of ill relatives, etc. as have been studies elsewhere⁵⁴ and might have provided a more complete model for family burden. It was not possible to collect comprehensive information on burden in our study in view of limited resources and possible administrative burden on the respondents. Further studies should be guided by this exploratory investigation and investigate predictors of family burden thoroughly.

However, despite these limitations, the study provides essential and hitherto unavailable understanding of the determinants of family burden of chronic illnesses in Singapore. The association of mental disorders among the family members of people with chronic illness highlights the psychological impact of caregiving. Besides the use of well established instruments for collecting information, other strengths of this study are the high response rate, large sample size and inclusion of all chronic illnesses in the study of care burden using a community sample of adults belonging to multiple ethnicities.

Conclusion

Acquiring a better understanding of the family burden has become increasingly important as families adopt a major role in the care of their relative. The prolonged nature of chronic illnesses that are likely to deteriorate over time and the fact that caregivers themselves would be getting older over time and would experience adverse physical and psychological strains exerts a huge burden on society.⁵⁵ This compound burden and the evidence that caregivers' subjective perceptions predicts the institutionalisation of people with chronic illnesses⁵⁶ have made it imperative to plan for interventions targeted towards reducing the burden of family caregivers. For this, sound understanding of the determinants and risk factors of burden of care are necessary.

A multi-factorial approach is essential to reduce the impact of burden. Determinants of burden such as experiences of dysthymia and perceived social support suggest that psychoeducational and psychosocial interventions targeted at the closest family members and friends could have positive effects for relieving caregiving burden. At present, there are limited support groups for chronic illnesses in Singapore (<http://www.aware.org.sg/support-services/support-groups/>). Services such as mutual support and self-help groups based on shared experience of affected people and professionals and peer support groups in the community could serve an important role in the wellbeing of family caregivers.

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