

Distress tolerance, psychosocial burden and its relationship with self-management of health in women with mental illness

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Summary

Objectives

This study was conducted to explore the relationship of caregiving burden, distress tolerance with self-health care among mentally ill women.

Materials and Methods

One hundred women with mental illness in remission were recruited and assessed with socio-demographic and clinical proforma, Distress tolerance Scale (DTS), Zarit Caregiver Burden Interview (ZBI) and Effective Consumer Scale (EC-17).

Results

The mean score of ZBI was 28.34 ($SD \pm 19.83$) and the mean score of DTS scale was 26.80 ($SD \pm 12.07$). The score of DTS was higher in the group without a family history of substance ($MU = 532.50$, $Z = -2.711$, $p = .007$), in those who remained untreated before the on-going treatment ($\chi^2 = 4.811$, $df = 1$, $p = .028$), and in the group with less awareness of treatment options ($\chi^2 = 4.072$, $df = 1$, $p = .044$). Linear multiple regression analysis ($R^2 = .215$, $df = 4$, $F = 6.443$, $Sig. = .000$), showed that the score on burden was negatively associated with tolerance ($\beta = -.416$, $t = -2.368$, $p = .020$), and positively associated with regulation ($\beta = .596$, $t = 3.742$, $p = .000$) sub-scale of ZBI. The level burden was negatively associated ($\beta = .280$, $t = 2.795$, $p = .006$) with the score of EC-17, and the score on tolerance subscale of ZBI was positively associated ($\beta = -.548$, $t = -3.239$, $p = .002$) with the score of EC-17.

Conclusions

The finding of this study indicates that mentally ill caregiving women had significant caregiving burden, and tolerated high distress. Caregiving burden was inversely associated with ability to tolerate distress and positively associated with emotional dysregulation. Self-management of health was negatively associated with severe level of burden and positively associated with ability to tolerate distress.

Key words

Distress tolerance • Psychosocial Burden • Women's mental health

Introduction

Stress is any stimulus (e.g. environmental or life events, etc.) that impinge on individual's reactions to stressful events, or a mismatch between the demands placed on the individual and the ability to cope with the demands^{1,2}. The stress becomes distress when it is unwanted, unexpected and ongoing, due to life changing events or situations. Distress tolerance (DT) is perceived as/or actual capability to tolerate aversive emotional and physical experience³. DT is an individual's evaluation and expectations about experiencing distress and associated with a tendency to alleviate or escape negative emotional experience⁴. DT is considered as a transdiagnostic risk, maintenance or preventive factor of psychological disorders³. Relationship of distress tolerance and self-management of health

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is not yet explored. A report reveals that the level of DT may mediate medication adherence and health seeking behaviour^{5,6}. Assessment of DT is challenging due to lack of consensus regarding the conceptualization. In this study, we have used Distress Tolerance Scale (DTS) to measure the Tolerance (individual's perception of ability to tolerate stress), Absorption (the degree to which an individual is consumed by negative emotions), Appraisal (the individual's assessment of the tolerability of the stress), and Regulation (the individual's feeling of urgency to do something to alleviate the negative emotion) after translating it to a local language (Kannada)⁴. This tool is considered appropriate to measure distress tolerance in comparison to other methods (e.g. persistence in arithmetic tasks, breath holding, and CO₂ inhalation and holding hand in cold water etc.) , particularly in population suffering from mental illness, and has been used in Indian population⁷.

The burden is the appraisal of the balance between the level of care demands, the level of resources available, and quality of caregiver-care recipient relationship⁸. The burden of care is the discomfort experienced during caregiving by the caregivers in the domains of physical health, psychological well-being, finances, and social life that affect the life of the care giver⁹. The burden was initially conceptualised as unidimensional, and later understood to be a multidimensional construct¹⁰. Burden of caregiving is known to affect physical and mental health of caregiver^{11,12}. Researchers have focussed more on ill effect of caregiving burden on caregiver health, and the relationship of caregiving burden and self-management of health is unexplored. Reports indicate that self-management of health is poor among caregivers¹³. There are challenges in the assessment of burden due to cultural, ethical, religious and other personal values. No unified approach is devised for its measurement, and there is little agreement on its definition¹⁴. To assess the burden of care, we have used Zarit Caregiver Burden Interview (ZBI) in this study (after translating to a local language, Kannada), a tool that is used in the Indian population¹⁵.

Self-management of health is "engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes"¹⁶. It is performed by patients to manage their own illness (not what the clinician does) such as making a choice, to practice new health behaviours, and to maintain or regain emotional stability¹⁷. Self-management of health depends upon multiple factors such as the necessary knowledge and skills, and the confidence to manage effectively their condition¹⁸. A report from India reveals that among general population, more than half people

with physical illness do not practice self-care¹⁹. To empower the health care recipient with health care skill for better outcome of illness is the need of the hour²⁰. In developed countries attempt have been made to develop specific self-management interventions to reduce or prevent recurrence of mental ill health and to help challenge existing perceptions and enhance the reputation of people with a psychiatric diagnosis as being capable citizens^{21,22}. Though attempt has been made to reduce the burden of caregivers, to optimise their overall health, but so far, the self-management of health among caregivers is unexplored in India.

The relationship of distress tolerance and caregiving burden with self-management of health in women is unknown, particularly if they also have a mental illness. Several studies reported a higher level of psychosocial distress among Indian women²³⁻²⁵; who are the major informal caregiver, facing role overload, poor health literacy, poor health care facility leading to poor psychological and physical health^{11,12,26-29}. Thus, this exploratory study was carried out to explore the level of distress tolerance & burden, and its relationship with self-management of health among mentally ill women caregivers with mental illness in full remission for at least two months. We hypothesised that level of DT and burden are negatively associated with the self-management of health.

Materials and Methods

This hospital based cross sectional study was conducted in a tertiary care centre over a period of 6 months (November 2014 - April 2015). A total of 100 consecutive female patients, who were living in the community after an episode of illness, and coming for follow-up, were consecutively recruited as per selection criteria; all the participants subscribed informed consent. The inclusion criteria were females between the age of 18-65, an ICD 10 diagnosis of a mental disorder currently in remission for at least 2 or more months (as per treating psychiatrist), and currently living in the community with their family members and involved in caregiving of any family members. A patient with chronic physical illness or physical disability, intellectual disabilities and dementia were excluded from this study, as these conditions are known to interfere in caregiving due to the inherent nature of illness. The study was started after approval from the institute's ethical committee. Participants who met the selection criteria were evaluated with assessment tools in following order:

1. Sociodemographic & clinical proforma: This proforma included demographic and clinical details such as education, employment, socioeconomic status, religion, marital status, residence, family type, housing, diagnosis, currently living with, substance

- use in the family, number of family members living together, treatment sought before, and knowledge about available treatment;
- Distress Tolerance Scale (DTS): The DTS is a 15-item self-report measure of one's ability to tolerate psychological distress⁴. The measure contains four subscales: (1) Tolerance - perceived ability to tolerate emotional distress, (2) Absorption - attention being absorbed by negative emotions, (3) Appraisal - subjective appraisal of distress, and (4) Regulation - regulation efforts to alleviate distress. The scores of the scale range from 15 to 75, and found to be of good internal consistency ($\alpha = .92$ in the present sample), test-retest reliability, and discriminant validity. This instrument has been used in the Indian population¹⁵;
 - Zarit Caregiver Burden Interview (ZBI): This tool has been used to assess the psychosocial burden of caregiving⁹. The ZBI measures subjective burden, in terms of the degree to which the caregivers experience physical, psychological, emotional, social and financial problems because of their care-giving role. It is a multicultural validated tool, and available in different language. It contains 22 self-reported items that assess the frequency and impact of care burden. Score ranges from 0 to 88, and studies showed Chronbach's alpha ranging from 0.88 to 0.92 and test-retest reliability to be .71. A score between 0 – 20 indicates no burden, 21- 40 is mild to moderate, 41-60 is moderate to severe, and score between 61- 88 indicate severe burden. It assesses both personal and role strain¹⁵;
 - Effective Consumer Scale (EC-17): The EC-17 measures knowledge, attitude, and behaviour about self-management skills using 17 items with 5-point Likert-type scales ("never" to "always"). Item scores are summed and converted to range from 0 to 100, where 100 is the best possible

score³⁰. Cronbach's Alpha and test-retest correlations found to be over 0.90¹⁸.

Data analysis was done with SPSS version 16. Demographic and clinical characteristics were expressed with descriptive statistics. Since analysis of data distribution revealed skewedness, Kruskal-Wallis H test was used to know the group difference between three or more variables, while Mann Whitney U test was used for comparison between two groups. After normalising the data, score on subscales of distress tolerance & different severity of burden were analysed using multiple linear regression analysis, to find out if they can predict the value measure on self-management of health. The level of statistical significance was kept at $p < 0.05$ for all tests.

Results

Demographic characteristics

More number of participants were married (91%), Hindu (88%), belonging to nuclear family (86%), having a diagnosis of mood disorder (62%), did not receive any treatment earlier (90%), and were aware only about medication as the treatment option (64%). The mean score of age was 37.35 and duration of illness was 4.89 years (Table I).

Levels of distress tolerance and burden

We observed a mean score of 26.80 (± 12.07) on DTS and 28.34 (± 19.83) on ZBI. Mean scores on subscales of DTS were - Tolerance 5.65 (± 2.57), Absorption 5.29 (± 2.68), Appraisal 10.62 (± 5.08), and Regulation 5.24 (± 2.83) (Table I).

The sociodemographic variables that had a statistically significant group difference on score of DTS were - substance use in the family (present vs absent; $U = 532.50$, $Z = -2.711$, $p = .007$), treatment received (no treatment vs allopathic treatment; $\chi^2 = 4.811$, $df = 1$, $p = .028$),

TABLE I. Demographic and clinical feature.

	Minimum	Maximum	Mean	Std. Deviation
Age	20.00	61.00	37.35	8.91
Duration of illness	1.00	25.00	4.89	5.09
Number of family members	1.00	13.00	4.070	1.73
Score on Burden Interview	0.00	79.00	28.34	19.83
Score on Distress Tolerance Scale	4.00	51.00	26.80	12.07
– Tolerance subscale	0.00	13.00	5.65	2.57
– Absorption subscale	0.00	11.00	5.29	2.68
– Appraisal subscale	1.00	22.00	10.62	5.08
– Regulation subscale	0.00	14.00	5.24	2.83

and knowledge of treatment option (medication only vs medication and psychotherapy; $\chi^2 = 4.072$, $df = 1$, $p = .044$) (Table IIA-B).

Relationships of burden and distress tolerance

On linear multiple regression analysis ($R^2 = .215$, $df = 4$, $F = 6.443$, $Sig. = .000$) the score on ZBI had significantly predicted the value of score on Tolerance ($\beta = -.416$, $t = -2.368$, $p = .020$) and Regulation ($\beta = .596$, $t = 3.742$, $p = .000$) subscale of DTS (Table III).

Relationships of self-management of health with distress tolerance and burden

On linear multiple regression analysis ($R^2 = .200$, $df = 7$, $F = 3.287$, $Sig. = .004$), the severe level of burden had significantly positively predicted the value on score of EC-17 ($\beta = .280$, $t = 2.795$, $p = .006$), while score on tolerance subscale of DTS had significantly but negatively predicted the value of score on EC-17 ($\beta = -.548$, $t = -3.239$, $p = .002$) (Table IV).

Discussion

Demographic characteristics of this study were similar to the observation made in another study conducted in this centre³¹. In this study, mean duration of illness was nearly five years, and the number of family members

living together was four. Longer duration of illness and more number of family members to be taken care, may have bearing on the level of burden experience³².

Levels of distress tolerance and burden

In this study, we found a significant level of distress tolerance and burden. Among socio-demographic variables history of substance use in the family, history of any past treatment for on-going illness and knowledge about treatment option had a statistically significant association with distress tolerance.

Among women, Indian culture and tradition favours a higher tolerance of burden. Indian women experience a higher level of psychosocial distress as observed in this study²³⁻²⁵. They are the major informal unpaid family caregivers, particularly when they have a role of daughter-in-law, spouse and daughter (Role overload)²⁷⁻²⁹. Supportive care demands, emotional toll, the adverse impact of caregiving on their health are the main stressors related to the caregiver role³³. The burden increases further after the occurrences of a mental illness due to associated psychosocial and human rights issues, stigma, etc.³¹. We Hypothesize that significant level of distress tolerance observed in this study can be due to mastery, habituation or other method of coping to overcome the persistent burden³⁴. In this study,

TABLE IIA. Relationships of distress tolerance and demographic characteristics.

Relationship between variables		N (%)	Mean Rank	Sum of Ranks	Mann-Whitney U	Z	Asymp. Sig. (2-tailed)
DTS score* Education	Uneducated	41	45.67	1872.50	1.012	-1.389	.165
	Educated	59	53.86	3177.50			
DTS score* Employment	Unemployed	38	46.86	1780.50	1.040	-.984	.325
	Employed	62	52.73	3269.50			
DTS score* Socioeconomic status	Low	63	50.16	3160.00	1.144	-.154	.878
	Middle	37	51.08	1890.00			
DTS score* Religion	Hindu	88	50.81	4471.00	501.00	-.287	.774
	Muslim	12	48.25	579.00			
DTS score* Marital status	Single	9	60.33	543.00	321.00	-1.067	.286
	Married	91	49.53	4507.00			
DTS score* Residence	Rural	68	52.26	3553.50	968.50	-.884	.377
	Urban	32	46.77	1496.50			
DTS score* Family type	Nuclear	86	51.37	4418.00	527.00	-.746	.456
	Joint	14	45.14	632.00			
DTS score* Housing	Kaccha	18	46.83	843.00	672.00	-.593	.553
	Pakka	82	51.30	4207.00			
DTS score* Substance use in family	Yes	22	65.30	1436.50	532.50	-2.711	.007
	No	78	46.33	3613.50			

TABLE IIB. Relationships of distress tolerance and clinical characteristics.

Relationship between variables		n (%)	Mean Rank	χ^2	h^2	df	Asymp. Sig. (2-tailed)	
Diagnosis	F 10	3	32.83	2.299	.02	3	.513	
	F 20	7	62.00					
	F 30	81	50.47					
	F 40 & Other	9	47.72					
Living with	Parent	17	47.00	0.811	.00	2	.667	
	In- law	7	43.71					
	Husband	76	51.91					
Treatment received	1	No treatment	90	0.669	.00	1	.413	
		Magicoreligious	6					57.50
	2	Magicoreligious	6	4.92	0.574	.00	1	.449
		Allopaththic	4					
	3	No treatment	90	46.20	4.811	.04	1	.028
		Allopaththic	4					
Knowledge about treatment	1	Medication	64	3.023	.03	1	.082	
		Psychotherapy	5					20.00
	2	Psychotherapy	5	15.70	0.411	.00	1	.521
		Medication+ therapy	31					
	3	Medication	64	51.97	4.072	.04	1	.044
		Medication+ therapy	31					

TABLE III. Relationships of distress tolerance and burden.

Model	Unstandardized Coefficients		Standardized Coefficients			
	B	Std. Error	Beta	t	Sig.	
1	(Constant)	1.153	.182		6.323	.000
	Appraisal	.106	.319	.061	.331	.741
	Tolerance	-.775	.327	-.416	-2.368	.020
	Absorption	-.070	.432	-.042	-.162	.872
	Regulation	.966	.258	.596	3.742	.000

Dependent Variable: Burden Score. $R^2 = .215$, $df = 4$, $F = 6.443$, $Sig. = .000$.

participants employed multiple strategies (tolerance, absorption, appraisal and regulation) to buffer the burden. Indian women use multiple coping strategies such as relaxation, exercise, yoga, writing dairy, prayer, recreation with family, spending time with friends, reading books, travelling or outing, listening to music, etc. ^{35 36}. However, even if we reported high level of DT, the high score of burden may suggest that the tolerance was inadequate to neutralise the burden effect.

We observed that, those who did not have a family history of substance use disorder (78%) were significantly

more tolerant to distress. This finding can be explained with the biopsychosocial model of health and disorder ³⁷.

Substance use disorder in one family member is often associated with syndromal and subsyndromal mental health problem in other first-degree relatives that may determine the distress tolerance ³⁸. There is indirect evidence, that distress tolerance is less amongst the relatives of a patient with substance use disorder ³⁹.

Those who did not receive any prior treatment (except ongoing treatment) were more tolerant to distress, than

TABLE IV. Relationships of health seeking behaviour with distress tolerance and burden.

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	34.707	3.045		11.397	.000
	Mild burden	-3.238	2.940	-.124	-1.101	.274
	Moderate burden	-3.556	3.354	-.111	-1.060	.292
	Severe burden	13.241	4.737	.280	2.795	.006
	Tolerance subscale	-2.579	.796	-.548	-3.239	.002
	Absorption subscale	1.835	1.093	.406	1.679	.097
	Appraisal subscale	-.036	.470	-.015	-.077	.939
	Regulation subscale	.489	.769	.114	.636	.527

Dependent Variable: ECS Score. $R^2 = .200$, $df = 7$, $F = 3.287$, $Sig. = .004$.

those who received allopathic methods of treatment earlier. In this study, 90% of the participant did not receive any prior treatment; ongoing treatment was the initial treatment for their mental illness, and interestingly distress tolerance did not vary significantly with the diagnosis of depression. It is possible that the reported distress tolerance was related to other stressors than mental illness such as psychosocial, financial, occupational ones .

One interesting finding of this study was less distress tolerance among those having awareness of both medication and psychotherapy as treatment option (31% of participants) compared to those who were aware of medication as the only treatment option (64% of participant). This is contrary to the other reports, which suggest that tolerance is enhanced with more knowledge about illness ⁴⁰. Those with less distress tolerance might have explored the possible treatment option (pharmacotherapy and psychotherapy) in order to get rid of distress, or had more mental health literacy. A report from India revealed that women with low distress tolerance try to gain more information about a psychological problem ⁴¹.

Relationships of burden and distress tolerance

We observed that ability to tolerate the distress is significantly but negatively associated with the burden. This finding is consistent with other report ⁴². Role related burden in women is reportedly more than male, particularly if they are working out of home (in this study 62% were working women) ^{27,29}. Role overload, dependent care issues, quality of health, problems in time management and lack of proper social support are the major factors that determine the psychosocial burden among working women in India ²⁹. Greenhaus and Beutell (1985) categorise these issues in to three work-family conflict: (a) time-based conflict, (b) strain-based conflict, and

(c) behavior-based conflict. In this study, a high level of distress tolerance appeared to be a necessity in order to buffer the effect of the burden ⁴³. Nehushtan (2007) proposed that tolerance has three types of motives that may be operative in Indian scenario also ⁴⁴. They are: 1) Tolerance as a right - other has a right to do the wrong thing or because the other has a privilege not to be harmed, in spite of his repulsive features or manners; 2) Pragmatic tolerance- tolerant person thinks that in given circumstances, it is in her or society's best interest to do so. Pragmatic tolerance can be the result of informal as well as formal decisions, and 3) Tolerance out of mercy. The result of this study revealed that, the feeling of urgency to alleviate the negative emotion (Regulation) is positively associated with the burden. Gratao et al. (2012) observed that, the caregiver emotional distress and burden is interrelated ⁴⁵. Distress tolerance involves active affect regulation, deployment of attention and cognitive function, appraisals of distress, and modulation of responses to distress ⁴. Cognitive variables that mediate avoidance of negative emotional states are negative problem orientation, distorted beliefs about worry, and cognitive avoidance ⁴⁶. These cognitive variables together with a low level of distress tolerance may increase the likelihood of engaging in worry as an avoidance strategy ³. On the other hand, low distress tolerance may increase the appraisal of anxiety symptoms, and helps to perceive anxiety symptoms as aversive, maintain rigid & inflexible view about negative emotions (harmful, impossible to manage or cope with, intolerable) ^{47,48}.

Relationships of self-management of health with distress tolerance and burden

Contrary to our hypothesis, we observe that patients scored better on measure of self- management of health, if they had a severe burden or lower level of

tolerance. This finding may be explained by Common Sense Model (CSM) of self-management that posited that people try to make sense of a threat to their health in order to try to control the threat⁴⁹. Illness perception (the cognitive and emotional representations of symptoms and illnesses) is shaped by burden of the illness, sense of a threat to their health and coping behaviour that in turn determines self-management behaviour. The burden of the illness and the sense of a threat to their health depend upon the person & multiple factors such as the necessary knowledge and skills, and confidence to effectively manage their condition¹⁸. Thus, level of burden may have indirectly enhanced the self-management of health. More burden with less tolerance observed in this study appears to be consistent with CSM model of explanation. In conclusion, the result of this study showed that women with mental illness in remission have a high level of distress tolerance and burden. The ability to tolerate

stress (Tolerance) was negatively associated with the burden, while the feeling of urgency to alleviate the negative emotion (Regulation), positively associated with burden. Severe level burden was negatively associated, while the ability to tolerate stress was positively associated with self-management of health. Though our hypothesis appeared to be untrue, it should be interpreted in the background of following limitation of this study. Study design was cross sectional, conducted at tertiary care centre. High burden can be viewed as a part of Indian culture and reported only when it is affecting and severe.

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Conflict of interest

None.

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