Geriatric Disability and Perceived Family Burden

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ABSTRACT

Background
Institutional care of the physically and cognitively intact and yet, socially unsupported elderly disturbs the senior psychologically and questions society's ethical commitment in the care for the vulnerable. The present study aims to learn the dysfunctions of the non-sick elders and their caregiver's perceptions.
Methods
Forty inmates of the Geriatric Ward, Christian Mission Hospital, Madurai aged 65 years and above were studied along with their registered caregivers. Double-blind data collection was done using a socio-demographic data-sheet, the WHO Psychiatric Disability Assessment Schedule (WHO/DAS) and Family Burden Interview Schedule (FBIS). Data analysis involved numerical inferences and Pearson's correlation.
Results
Most of them were above 75 years, widowed and financially dependent. Women outnumbered men. They evinced only minimal dysfunction which was age and situation appropriate. Caregivers were predominantly financially-sound family members. One fourth was found to be non-family. Caregivers suffered varying domains of burden - particularly in family interaction, physical health and subjective burden. Correlations indicated that Overall Behavior was not significantly related to any domain of Burden. Global score correlated to disturbances in leisure activities, physical health and Subjective Burden of the caregiver.
Conclusion
The results indicate that individual and group therapy for the patients and for their caregivers might help them to resolve the misperceptions and reintegrate the elderly with their families.

Keywords: Geriatric in-patients – Psychological dysfunctions – Family burden – FBIS.
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Key Message - Elderly people's age-related dysfunctions are frequently perceived as burdensome. Caregivers should be psychologically supported to accept the senior's difficulties - to prevent their alienation and promote their social inclusiveness.

INTRODUCTION

Despite vast improvements in elderly-care such as in cancer, terminal illness, dementia and others,[1] physically and cognitively intact seniors are often socially unsupported and abandoned into institutional care. Families are increasingly nuclear in structure and outlook. Burden of psychosocial strains and family's unhealthy coping end up in 'non-integration' and alienation of the seniors. [2,3] Changing societal values and a prevalent acceptance of such neglect neutralize the corrective guilt and the disequilibrium gets stabilized. The present study aims to learn the healthy elder's dysfunctions and the caregiver's perceptions to enable their healthy reintegration.

MATERIAL AND METHODS

The study was conducted in the Geriatric Ward of The Christian Mission Hospital in Madurai. Patients admitted in the ward were brought by caregivers residing in and around Madurai - who meet the financial obligations of in-patient care. The study was aimed at understanding the various dimensions of dysfunctions of the in-patients, the burden experienced by the caregivers and their families and the determinants of both. The design of the study was approved by the Institutional Ethics Committee. Forty in-patients were selected randomly on meeting the following criteria:

Inclusion Criteria

1. Individuals should be aged 65 years or more.
2. Both the patient and family member should be willing to participate in the study. They were informed that data collection would be on their free will, that the details might not contribute to further therapeutic management and that confidentiality of the data would be assured.

Exclusion Criteria

1. Destitute patients and those with significant physical illness and/or cognitive impairment (including dementias) were excluded.
2. They should not suffer from any comorbid conditions such as substance abuse, mental retardation and others.

Each patient had been clinically evaluated by the psychiatrist on physical, behavioral and cognitive domains. The significant caregivers were interviewed during their hospital visits. Demographic details and family burden were made out by the psychologist. Dysfunctions were assessed by the medical officer looking after the Geriatric Ward for the previous six months. Both the psychologist and the medical officer were trained by the psychiatrist in the administration of the study tools. Double-blind data collection under the supervision of the primary psychiatrist was done individually using the following tools:

- Schedule for collecting the socio-demographic data.
- WHO Psychiatric Disability Assessment Schedule (WHO/DAS) [4] - It is a simple tool designed for studying in-patients and has seven areas - Overall dysfunctional behavior, Social role dysfunction, Behaviour in the hospital, Assets and liabilities, Home atmosphere, Social support and Global evaluation. This tool has been extensively used in research and has a good construct validity and inter-rater reliability.

- Family Burden Interview Schedule (FBIS) [5] - Has been used extensively in Indian research. This schedule measures the following areas - Financial Burden, Effect on family routines, Effect on family leisure, Effect on family interaction, Effect on physical health, Effect on mental health and Subjective burden. Each item is measured on a 3-point (0: No burden; 1: moderate burden and 2: severe burden) scale. The tool has a good reliability and validity.
- Data was analyzed using numerical inferences and Pearson's correlation.

RESULTS

The study was conducted in the Geriatric Ward of The Christian Mission Hospital, Madurai. The ward offers a paid service that is financially viable such that the economic middle class can afford to meet the moderate financial commitments. The patients were examined by the physician and the psychiatrist prior to admission was to screen off those who required an intense medical management regimen. Socio-demographic details of the patients (Table 1) indicate that almost three fourths of them were above 75 years. Women outnumbered men. Two men and one woman had living spouses. Most were financially dependent and nine were living alone.

Caregivers were predominantly from within the family. Spouses, children and grandchildren helped four fifths of the patients (Table 2). Yet, one fifth of the patients were looked after by non-family members including friends. All of them had a reasonable income. Six of the caregivers themselves were financially supported by their own children. Three patients were brought unmanageable; twenty two patients for mild ailments and rest were literally 'dumped'. Only two caregivers were willing to take them back home permanently.

Assessment of Dysfunction was done using WHO/DAS (Table 3). Dysfunction in social roles (Section 2) was left out as most areas of the schedule were not applicable to these patients as evidenced by their socio-demographic profile.

Moreover, the WHO/DAS manual forbids scoring this dimension if the patient had been in the hospital for more than three months. Social support (both Seeking and Receiving) was sought by only one patient and hence not included in the table. Comparison with the maximum scores indicated that dysfunctions were at a minimal level.

Overall behavior evinced minimal disturbances and ward behavior indicated that they did not cause difficulties in management. Nurses opined favorably on the dependability of their behavior. Occupational involvement and contacts with the outside were poor. Specific assets which reflected their initiative and interpersonal support-building were poor and their liabilities did not predict a dysfunctional level. Home atmosphere evinced a prevailing non-integration of the patients. Study of components of Overall Behaviour showed that all of them were significantly correlated with each other (Table 4).

The caregivers suffered a moderate degree of burden (Table 5). Various domains of burden evinced a varying and yet, significant degree of suffering. Disturbances in family interaction, Effect on physical health of caregivers and Subjective burden were more disturbed compared to Effect on mental health and financial burden.

Correlations between Experienced Burden and areas of Dysfunction indicated that Overall Behaviour was not significantly related to any of the domains of Burden (Table 6). Global score was significantly correlated to Effect on leisure activities, Effect on physical health of caregiver and Subjective Burden of the caregiver. Effect on Mental Health of the caregiver was significantly related to Ward Behaviour and the nurse's evaluation scores.

		Number of Patients (N = 40)	%
Age	65 to 75	11	27.5
	76 to 85	21	52.5
	86 and above	08	20.0
Sex	Men	07	17.5
	Women	33	82.5
Marital Status	Married	03	7.5
	Widowed	35	87.5
	Unmarried	02	5.0
Financial Status	Dependent	34	85
	Independent	06	15
Family Type	Nuclear	03	7.5
	Joint	06	15.0
	Extended nuclear	22	55.0
	Living alone	09	22.5

Table 1: Socio-demographic details of the in-patients

		Number of Caregivers (No = 40)	%
Relation to the patient	I degree	26	65.0
	II degree	05	12.5
	Others	09	22.5
Care-givers' income	Below Rs.10000.	08	20
	10000 to 30000	21	52.5
	Above Rs. 30000	05	12.5
	No income of their own	06	15
Reason for admission	Unmanageable	03	7.5
	Logistic difficulties in care-giving	15	37.5
	Uninterested	22	55
Willingness to take back	Yes	02	05
	Not willing	38	95

Table 2: Socio-demographic details of the caregivers

Areas of Dysfunction		Mean Score (N = 40)	S.D.	Maximum Possible Score
Overall Behavior	Self-Care	1.35	0.95	5
	Paucity of Activity	1.20	0.69	5
	Slowness	1.30	0.57	5
	Social Withdrawal	1.28	0.88	5
	Raw Score	5.13	2.64	20
Behavior in Hospital	Ward Behavior	4.19	4.50	24

	Nurses' Assessment	0.65	1.73	09
	Occupational Involvement#	0.22	0.25	17
	Contact with the Outside#	0.30	0.82	14
Assets and Liabilities	Assets#	0.6	0.63	5
	Liabilities	0.95	1.04	3
Home Atmosphere		0.28	0.96	10
Global Score		1.90	2.04	5

Table 3: Psychological dysfunctions of geriatric in-patients

Dysfunctions were studied with WHO Psychiatric Disability Assessment Schedule.
# Indicates that higher the score, less would be Dysfunction.

	Underactivity	**Slowness**	**Social Withdrawal**
Self-Care	0.56*	0.52*	0.56*
Underactivity		0.83*	0.84*
Slowness			0.66*

Table 4: Inter-correlations between overall behavior disturbances

Only 'γ' values of Pearson's correlation are given.
Df = 38. * p< 0.001

Domains of Burden	**Mean Score (N = 40)**	**S.D.**	**Maximum Possible Score**
Objective Burden			
Financial Burden	3.55	2.45	12
Disturbances in Family Routines	4.03	2.47	10
Disturbances in Leisure Activities	3.43	1.77	08
Disturbances in Family Interaction	6.28	2.48	10
Effect on Physical Health	2.18	1.60	04
Effect on Mental Health	0.43	0.90	04
Subjective Burden	1.58	0.71	02
Total Burden	**21.5**	**7.66**	**50**

Table 5: Burden experienced by the caregivers

Family burden was assessed using the Family Burden Interview Schedule (FBIS).

Domains of Burden	**Self - care**	**Paucity of Activity**	**Slowness**	**Social Withdrawal**	**Ward Behavior**	**Nurses' Score**	**Global Score**
Objective Burden							
Financial Burden	.22	.16	.19	.01	.23	.18	-.05
Disturbances in Family Routines	.06	.12	.20	.08	.03	-.14	-.24
Disturbances in Leisure Activities	-.09	.18	.20	.15	.09	.07	.36*
Disturbances in Family Interaction	.21	.04	.14	-.01	.09	-.24	.23
Effect on Physical Health	.06	.01	.08	-.09	.21	.03	.35*
Effect on Mental Health	.09	.23	.20	.14	.45**	.68***	.14

Subjective Burden	.23	.18	.26	.11	.27	.04	.31*
Total Burden	**.18**	**.18**	**.29**	**.07**	**.26**	**.01**	**.19**

Table 6: Correlates of burden domains with the patient's dysfunction

Only 'γ' values of Pearson's correlation are given.
Df = 38. * p< 0.05; **p<0.01; ***p< 0.001

DISCUSSION

The study was designed to involve the 'relatively intact' elderly in the Geropsychiatry Ward. Clinical screening by the senior author followed the aforementioned inclusion criteria. Patients had only age-appropriate physical changes such as slowness and senile cognitive disturbances which did not interrupt their day to day activities. None of them suffered from any significant physical ailment. Assessment of dysfunction in comparison to the possible maximum score showed that the self-care, underactivity, slowness and social relations evinced only a minimal dysfunction. Ward behavior and the nurses' assessment showed that they were functioning appropriately. Occupational involvement was poor but was age and culture appropriate. Self-care, Paucity of activity, Slowness and Social relations were highly inter-correlated indicating an underlying common element either of senile biological changes or a resigned lack of motivation because of the perceived rejection and prolonged institutional care. Functional levels did not necessitate their stay in the hospital as in patients. Geriatric wards are more often 'health-wards' than 'sick wards', but the institutionalization brings about isolation and poverty of social connectivity.

The typical patient was above 75 years, widowed, financially dependent and a woman. [6,7] Women outnumbered men significantly, but only two of them had a source of income compared to the financial independence of four of the seven men. Though dependent and devoid of significant dysfunctional problems, preponderance of women and unwillingness of the family to take them back home were reflective of a more interpersonal rejection. Total absence of sons in law or daughters in law in the list of caregivers and even among visitors underlined the interpersonal schism among the relations. Nine of them were living alone though five had hailed from extended nuclear families. All were looked after by non-family members. Living in a family did not guarantee social integration and paradoxically, isolation did not deny social integration.[2]

Caregivers were essentially from the family though one fifth was not filially obliged. They were financially resourceful and even those who did not have an income of their own, were supported by their own children. Only three patients were admitted initially for unmanageable behavior but they improved well subsequently. The caregivers mentioned that other commitments and an inability to look after the aged were the reasons behind their decision. More than half of the caregivers openly communicated total lack of interest in keeping the aged at home and most of them were unwilling to take them back. Only two patients with a sound financial background were accepted back into the families by their wives.

Burden experienced by the caregivers in various domains was compared to the possible maximum scores in each area. Financial burden was not very disturbing but the presence of the aged member in the family was experienced as significantly interfering with their family routines, their leisure activities and their interactional pattern. The last two were very sensitive to the strain on the family equilibrium and were compromised at the earliest and for a long duration. Effect on physical health was considerable whereas mental health was not adversely disturbed. This has to be viewed in the context of the tendency of the native population to somatize the psychological disturbances because the former are culturally weighed in and psychological symptoms are viewed

more as weaknesses. [3,8] Significantly, the perceived subjective burden of the caretakers was severe.

Correlations between the areas of dysfunction and domains of experienced burden showed that components of overall behavior were not significantly related to any of the domains of the burden. Ward behavior and nurses' assessment were significantly correlated to burden on mental health. More dimensions of behavior involving interpersonal relatedness were assessed in scoring ward behavior and nurses' assessment reflected dependability of the patient's potential behavior. Both reflected certain expectations of others on the patient's behavior and the patient's inherent failure to meet them reflected the psychological consequences on the caregivers. Global score indicates a judgment of a patient's social functioning appropriate to his native context. It was significantly predictive of disturbances in family leisure, effect on physical health and subjective burden.

The study indicated that normal aging has been increasingly perceived as strainful by caregivers. The experience is global.[3] Decreasing birth rates and increasing life expectancy have altered the equilibrium with increasing old age dependency and lessening youth contributions. Funding by Government might necessitate diversion of the vital developmental resources.[6,9] Care in a nursing home is expensive and less satisfactory for the elderly.[1] Observations in semi-urban areas during a geropsychiatric survey three decades ago evinced a healthy social responsibility in the care of the elderly. Even the destitute were collectively looked after by the community.[10] Social participation in the care of dependents has been increasingly sparse and unfortunately the elderly are the most vulnerable.

CONCLUSION

Innovative 'Time Bank' experiences in St. Gallen, Switzerland envisages retired volunteers deposit hours of elderly care and in return they can use it for their own care later in life. Social service costs are less and it brings people together, fostering camaraderie. The concept has been replicated in many western countries such as the U.K., Israel, the U.S.A., Turkey, Spain and Germany. 'Fureai kippu' (Caring Relationship Tickets) in Japan and China accepts younger family members earning credits for helping elders and transferring them to parents living elsewhere.

India's time bomb also has begun to tick louder Similar trials are being experimented in Kochi. Migration to cities, working women, dependence of the elderly and lack of social support make it an essentially urban phenomenon. Community's acceptance and supportive integration mitigate the suffering among the rural elderly but cracking fissures are visible. The native joint family system could still be a better answer; but may not be always feasible. The government has enacted several laws in the protection of the elderly by their 'significant others'. But legal coercion is easily side-stepped. Blossoming acceptance and emergent responsibilities should mark the filial bindings. The results of the study indicate that individual and group therapy for the patients and for the caregivers might help them resolve the issues and reintegrate the elderly with their families. Bringing people together and helping the unproblematic elderly live in 'their own homes' should be the best corrective measure. The evening of their lives should continue to be productive, independent and fulfilling.

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