



Disability and quality of life among elderly persons with mental illness



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ABSTRACT

The present study was undertaken to understand the level of disability and quality of life of elderly persons with chronic and persistent mental illnesses and to compare it with those who were elderly but well with no illness. For the purpose 200 elderly persons with mental illness (PMI), attending psychiatric services were included in the study. A comparison group of 103 well elderly persons was drawn from the same study area as control group (CG). They were assessed using WHO-DAS and WHOQOL-BREF. Results revealed that PMI experienced higher disability compared to the CG. Deficits in the domain of moving around, getting along with people, engaging in life activities and participation in society contributed most to the high level of disability in the PMI group. PMI from rural area had higher disability compared to the urban group. As for QOL, elderly PMI had a poor quality of life compared to the CG. Quality of life was found to be negatively associated with level of disability. Higher the level of disability, lower was the quality of life. The authors opine that persons with chronic mental illness continue to experience psychiatric disability in old age and this cannot be attributed to normal aging. Level of disability has a negative impact on their quality of life.

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1. Introduction

Studies on health status of aging population demonstrate that there is a direct correlation between health problems and advancing age, though the health status of the aged varies from individual to individual and between gender. (Bali, 1995; Chengti, 2007; Kusuma and Reddy, 1999; Ladusingh and Bijaya, 2004; Mohanan et al., 2007; Nagarathamma, 2003). Reports are also available on issues of elder abuse (Khan, 2007; Prakash, 2003; Vaswani, 2001; Veeton, 2001). Dementia is another condition which has been widely researched and reported in this population (Gambhir et al., 2003). Though there are reports of high prevalence of depression among the elderly (Niriya and Jhingan, 2002; Patil et al., 2003), not much is reported about problems encountered by elderly persons with severe and persistent mental illnesses like chronic schizophrenia and affective disorders.

There are studies that report different rates of psychiatric morbidity among geriatric population in India. The results vary depending on the geographical area and methodology adopted in

these studies (Bhogle and Sudarshan, 1993; Ganguli, 2000; Gupta, 2006; Rao, 1993). There is lack of adequate research data on the mental health conditions, especially Schizophrenia and Affective disorders among geriatric population. Most of the studies have focused on the adult population and exclude the elderly ill population. In addition, care services also lack this perspective. Elder care services focus on the medical needs and very less information is available in terms of care services for the elderly mentally ill persons.

Disability due to mental illness can be devastating and can erode or prevent the development of functional capacities with respect to personal hygiene, self-care, self-direction, interpersonal relationships, social transactions, learning and recreation. This is true of the geriatric population too. Most people who suffer from these conditions would need to take maintenance medication to keep well. Often these are missed due to the illness itself or due to associated cognitive dysfunction. Hence, close monitoring is essential to keep the symptoms at bay.

Psychiatric disabilities are most often invisible, unpredictable and are not consistent. They are usually associated with deficits in cognitive functioning. Moreover, the impact of psychiatric disability is not confined to the individual but affects other members of the family and their social circle. Level of disability in turn has an influence on the quality of life of this special

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population. Quality of life largely depends on the extent to which individuals have capacities and skills, opportunities and resources at their disposal by which they seek to fulfil their needs and attain their life goals. However, quality of life of persons recovering or those who have recovered from chronic mental illness in the geriatric population has remained a neglected area of research. Bali (2005) points out that research in the area of disability in old age is lacking in India. Tailoring services to the client's needs and improving the quality of life of this population poses a big challenge. Chronic mental illness compounded with ageing related problems present a grim situation. Very little information is available about their quality of life. Considering this gap in information the present study was carried out.

2. Aim

We aimed to compare the level of disability and quality of life of elderly persons with chronic mental illness with those of well elderly persons from a rural and an urban area.

Objectives:

- To assess the level of disability among elderly persons with chronic mental illness.
- To assess the quality of life of elderly persons with chronic mental illness.
- To compare the level of disability and quality of life of elderly persons with chronic mental illness with those without mental illness.
- To find out if there is any association between level of disability and quality of life.

3. Material and method

3.1. Sample

Persons with mental illness (PMI): A sample of 205 elderly persons (age 60 yr and above) diagnosed with chronic mental illness as per ICD 10 (WHO, 1992), both men and women, were included in the study. This group (PMI) included all those who were available at the time of study from an outreach program, psychiatric nursing homes, clinics and general hospitals, all within the catchment area. Only those who were not symptomatic at the time of study and those who could comprehend the instructions and questions and communicate their responses clearly were considered for the study. Diagnostic categories included Schizophrenia (all types), depression, Bipolar Affective Disorder, and Psychosis (unspecified). Persons with Epilepsy, Dementia, Addiction, or any other neurological conditions and those who were symptomatic were excluded from the study.

Control group (CG): A control group of elderly persons without mental illness was included in the study for comparison purpose and to see if the disability and the quality of life seen among the mentally ill persons can be attributed to normal aging only or if the mental illness contributed to additional disability and impacted the quality of life. A stratified random sample of 100 elderly persons (aged 60 yr and above), both men and women, without mental illness, epilepsy, dementia and or any other neurological disorder was drawn from both urban and rural areas from where most of the persons with mental illness were selected. This constituted the control group.

3.2. Tools

Following tools were used for the main study:

A socio-demographic data sheet. This included questions to elicit information about socio-demographic characteristics, history of

mental illness and treatment, screening questions for neurological illness (Gourie Devi et al., 2004), Dementia Screening Questions (AD8, Galvin et al., 2005), and screener for medical conditions (Miller et al., 1992). The control group was screened for mental illness using 5 screening questions on hallucination, delusions, behaviour (social withdrawal, aggression/violence, talking/laughing to self, other strange behaviour, and behaviour deficits) in place of history of mental illness.

WHO disability assessment scale (WHO-DAS-II 2000). This instrument consists of items pertaining to six life domains and has a total of 36 items. These are: Understanding and communicating; Getting around; Self-care; Getting along with people; Life activities; and Participation in society. The items are rated on a five point scale ranging from 'No Disability' to 'Extreme Disability'. The scale was developed by WHO for use in culturally different settings. The tool has been reported to be highly reliable and valid tool. Chronbach's alpha ranges from 0.79 to 0.98 for the domains and for the full scale it is 0.96. Test-retest reliability for the full scale is 0.98. Correlation coefficient for concurrent validity varies between 0.45 and 0.65 (Ustun et al., 2010). Prior permission was sought from the World Health Organization to use the tool for the study.

The test was translated into Kannada (local language) for the purpose of the study only. We followed the standard procedure of two independent forward translations from English to Kannada, synthesis, back translation, expert committee review, pre-testing, review and finalization.

WHO quality of life-Brief version (WHO-QOL-BREF, 2004). This instrument has items for overall quality of life and general health and other items which pertain to four domains i.e. Physical domain, Psychological domain, Social domain, and Environment domain. High reliability and validity have been reported for this tool. Chronbach's alpha ranges from 0.63 to 0.84 for the domains. High discriminant validity ($F=96.3$, $P < 0.0001$) and construct validity (Pearson correlations $r=0.46-0.67$) have been reported (Skevington et al., 2004). This scale is available in 19 languages including Kannada. The Standardized Kannada version of the test was used for the study. Items on the scale are rated on a 5 point rating scale. Higher the score better the quality of life. Total attainable best score on the scale is 130. A score of 78 corresponds to average level on the scale. Prior permission was sought from the World Health Organization to use the tool for the study.

3.3. Ethical concerns

Informed written consent was taken from the participants. Participation in the study was voluntary and only those who consented to participate in the study were included in the sample. They were also given the choice to discontinue if they wished to. They were assured of the confidentiality of the information shared by them. During the interview anyone who needed, were referred for professional help. Prior permission was taken from the psychiatric centres for collection of data.

Ethical approval for the study was provided by the Institutional Research Review Board and Institutional Research Ethics Committee of Richmond Fellowship Post Graduate College for Psychosocial Rehabilitation. Upon submission of the project, the study was also cleared by the Research Review Board of Indian Council of Medical Research that also provided funding for this research.

3.4. Procedure

Individual case records available at the respective consultation centres provided the basic clinical information. In addition detailed Case History was gathered and Mental Status Examination was carried out by the trained research officers of the project under

supervision of chief investigators. The project officers who were recruited were postgraduates and had three to four years of experience of working in a mental health project. They were trained in interviewing skills and use of the tools during the first phase of the study. Following the screening, individuals who fulfilled the inclusion and exclusion criteria were individually interviewed using the tools and whenever required information was corroborated from the family members.

3.5. Statistical analysis

Socio-demographic data was analysed to understand the characteristics of the sample. Responses on WHO-QOL-BREF and WHO-DAS were scored as per the guidelines given for scoring. Descriptive statistics were calculated for these scores. QOL scores followed Normal distribution pattern while the scores for disability did not. Disability scores and QOL scores were categorized according to quartile distribution i.e. 1st quartile, 2nd quartile more than 2nd quartile. Suitable parametric and non-parametric tests have been applied for comparisons. *t* test, Mann–Whitney test and χ^2 test were applied for the purpose.

4. Results

4.1. Socio-demographic profile

Of the total sample of 205 persons with mental illness (PMI) 200 completed the assessments. Among this group 113 (56.5%) were from urban area and 87 (43.5%) were from rural areas. The age of the participants was 60 yr and above. Of the sample 84 (42%) were men and 116 (58%) were women. In the total sample 54.5% participants were illiterate. In the rural sample 85.1% people were illiterate whereas only 31.5% of the urban participants were illiterate. The socio-demographic profile of the two groups is presented in Table 1. The control group of 100 well individuals was comparable to PMI group in their socio-demographic characteristics.

4.2. Diagnosis

A total of 60.5% of the participants had a diagnosis of depression. Depression was found in 33.5% of the urban sample and 27% in the rural sample. 29% of the total sample had a diagnosis of schizophrenia, of them 16.5% and 12.5% were from urban and rural sample respectively. Psychosis (unspecified) was diagnosed in 2% of the sample, 0.5% from the urban sample and 1.5% from the rural sample. Diagnosis of Bipolar affective disorder was found in only 2% of the sample and only in the urban sample. Schizo-affective disorder comprised 6%, and anxiety comprised 1.5% of the sample.

4.3. Physical health

Physical morbidities that were found among the participants of the study were also analysed. The reported morbidities were diabetes mellitus (PMI-19%, CG-18.4%); sensory impairment (PMI-46%, CG-47.6%); substance use–Nicotine/alcohol (PMI-43%,CG-15.5%); Bone related–aches, pains, arthritis (PMI-51%,CG-69.9%); respiratory and kidney related (PMI-10%, CG-20.4%); cardiac related (PMI-16.2%,CG-7.8%); endocrine related (PMI-3%, CG-1.9%). The problems reported by the PMI group was similar to those reported by the CG. Common physical morbidities of the study population were similar to those reported in the literature (Goldman, 1999; Yvonne De Silva et al., 2002; Timothy et al., 2003; Gurvinder et al., 2004).

4.4. Disability

Disability was assessed using WHO-DAS. The mean disability score for PMI group was 30.8 suggesting Moderate level of disability. However, the rural group scored higher (36.64) than the urban group (26.17) suggesting higher disability among the rural group. The difference was statistically significant ($P=0.001$). Moderate disability was found in the domains of Understanding and Communicating, Getting Around and Getting along with

Table 1
Socio-demographic characteristics of PMI and CG.

Variables	Type of groups		Total	χ^2	P
	CG	PMI			
Age	Upto 69	66 (64.1%)	131 (65.5%)	0.06	0.806
	70+	37 (35.9%)	69 (34.5%)		
Gender	Male	38 (36.9%)	84 (42%)	0.737	0.391
	Female	65 (63.1%)	116 (58%)		
Religion	Hindu	93 (90.3%)	190 (95%)	5.416	0.247
	Muslim	6 (5.8%)	6 (3%)		
	Christian	4 (3.9%)	2 (1%)		
	Others	0 (0%)	2 (1%)		
Education	Illiterate	49 (48.1%)	109 (55.1%)	13.871	0.054
	Primary/Middle	31(30.4%)	41 (20.7%)		
	S.S.L.C.	18 (17.6%)	25 (12.6%)		
	P.U.C.	2 (2%)	2 (1%)		
	Technical	0 (0%)	2 (1%)		
	Graduate	2 (2%)	15 (7.6%)		
	Post graduate	0 (0%)	4 (2%)		
Marital Status	Single	3 (3.1%)	25 (12.6%)	77.903	0.000
	Married	45 (45.9%)	155 (77.9%)		
	Widowed	45 (45.9%)	13 (6.5%)		
	Others	5 (5%)	6 (3%)		
Family type	Single	57 (58.8%)	167 (86.1%)	31.181	0.000
	Joint	35 (36.1%)	27 (13.9%)		
	Extended	5 (5.2%)	0 (0%)		
Total		103	200		

PMI = Persons with mental illness; CG = Control group.

Table 2

Disability scores of normal (CG) and mentally ill persons (PMI) according to domains.

Domain	Type of case	N	Mean	SD	Z (Mann–Whitney)	P
Understanding and communicating	CG	100	21.65	23.59	1.213	0.225
	PMI	195	26.97	28.36		
Getting around	CG	98	28.83	29.57	3.725	0.000*
	PMI	193	39.90	27.02		
Self-care	CG	101	10.79	20.13	1.302	0.193
	PMI	192	15.63	25.90		
Getting along	CG	103	9.81	19.50	5.234	0.000*
	PMI	193	22.33	27.20		
Life activities	CG	101	30.89	36.11	2.175	0.03*
	PMI	196	37.14	32.63		
Participation in society	CG	96	25.56	23.50	3.786	0.000*
	PMI	197	32.83	18.71		
All domains	CG	90	21.65	19.49	3.84	0.000*
	PMI	170	30.85	20.94		

PMI = Persons with mental illness; CG = Control Group of normal persons.

* P significant.

People. Domains of Life Activities and Participation in Society revealed High disability while Self-care domain revealed Mild disability. Rural PMI group was found to experience significantly higher disability than the urban PMI group in all the domains except Self-care

4.4.1. Disability among PMI and CG

Disability among persons with mental illness was compared with level of disability among persons without mental illness. PMI were found to experience higher disability compared to the control group ($P = 0.000$). There was a statistically significant difference in scores on all domains except domain of Understanding and communicating and domain of Self-care as presented in Table 2.

4.4.2. Disability and gender

When gender was considered, women were found to have higher disability in two domains, namely Understanding and communicating and Getting around ($P = 0.042$ and $P = 0.020$, respectively). The differences were statistically significant. Women seem to experience significantly higher disability than men as also reported in other studies of adult population (Ramaprasad et al., 2011).

4.4.3. Disability and age

The study sample was categorized into two age groups namely 60 to 69 yr and 70 yr and above. The two age groups were compared for level of disability. The older age group had higher disability. The difference was statistically significant in four domains i.e. Understanding and communicating ($P = 0.047$), Getting around ($P = 0.011$), Self-care ($P = 0.013$), and Life activities ($P = 0.010$).

4.5. Quality of life

Quality of life of the total sample was at slightly below average level with a mean score of 75.2. Of the total sample 59.5% scored below the cut-off expected average of 78 and 40.5% scored above the cut-off score. The rural sample had a mean score of 70.14 whereas the urban sample had a mean score of 79.08. The scores suggest that the rural sample had a significantly lower quality of life compared to the urban sample and the difference was statistically significant ($P = 0.00$). The physical domain and the

Table 3

Quality of life scores of normal (CG) and mentally ill persons (PMI) by domains.

Domains	Groups	N	Mean	SD	T	P
Physical	CG	103	22.59	6.46	5.225	0.000*
	PMI	200	18.97	5.31		
Psychological	CG	100	20.48	5.26	2.747	0.006*
	PMI	200	18.88	4.51		
Social relationship	CG	103	11.34	2.47	1.766	0.078
	PMI	200	10.75	2.92		
Environment	CG	98	28.01	5.58	2.136	0.034*
	PMI	200	26.60	5.23		
All domains	CG	95	82.47	17.02	3.849	0.000*
	PMI	200	75.19	14.21		

PMI = Persons with mental illness; CG = Control Group of normal persons.

* P significant.

environment domain seem to have contributed the most to the low average overall QOL, especially to the poor QOL of the rural sample.

4.5.1. QOL of PMI and CG

QOL of persons with mental illness was also compared with that of a control group (Table 3). The results revealed overall better QOL for the normal group. The difference in scores was statistically significant. The differences were significant for three domains i.e. Physical, Psychological, and Environment domains.

4.5.2. QOL and gender

There was no significant difference in the QOL when gender was taken into consideration.

4.5.3. QOL and age

To find out the impact of further aging on quality of life the sample was grouped into two age categories i.e. 60 yr to 69 yr and 70 yr and above. Age was found to have an impact on the QOL. The higher age group of 70 years and above had a poorer QOL compared to the 60–69 years age group. Physical health and Environment contributed to the poor QOL at the higher age level. The difference in the two age groups is statistically significant for the Total QOL ($P = 0.009$) as well as Physical domain ($P = 0.000$) and Environment domain ($P = 0.022$).

4.6. Quality of life and disability

Quality of Life was found to be negatively associated with level of disability ($\chi^2 = 76.306$, $P = 0.000$). The association was statistically significant. Lower the disability higher was the quality of life. This was irrespective of domicile and age of the participants as presented in Table 4.

5. Discussion

Chronic mental illness has its negative consequences on the life of the affected person as well as others closely associated with the individual. This is more so when the consequences continue and persist in old age. In the review of research on elderly persons with chronic mental illness, we found that very little attention has been given to understand the extent of psychiatric disability and quality of life of this population.

The results of the present study underline the fact that elderly persons with severe mental illness experience higher level of disability. Some skills and functions like self-care and understanding-communicating that are lost in the course of the mental illness show recovery with treatment. However, deficits in other skills like getting along with people, engaging in life activities, participating in society persist. The illness affects these functions and people do

Table 4
Association between level of disability and quality of life.

QOL groups (based on quartiles)		Disability score groups (based on quartiles)			Total
		Upto 14.50	14.51 to 24.50	24.51 and above	
Upto 66.00	N		2	42	44
	%		4.4	52.5	25.9
66.01–84.50	N	19	24	35	78
	%	42.2	53.3	43.8	45.9
84.51 and over	N	26	19	3	48
	%	57.8	42.2	3.8	28.2
Total	N	45	45	80	170
	%	100.0	100.0	100.0	100.0

$\chi^2 = 76.306, P = 0.000.$

not seem to recover these functions, even though they show improvement in other areas with treatment. Negative symptoms, which do not respond well to medication, could be one factor that contributes to the persistent higher disability in this group. Stigma associated with mental illness could be another factor that probably influences the recovery in these domains since these impede social interaction. This suggests that chronic mental illness does bring about disability which cannot be accounted for as normal aging or as being age related. The data also suggests that with further aging domains of understanding and communicating; and self-care also gets affected. With increase in age, even well persons exhibited certain deficits as part of aging and in the elderly mentally ill group the disability level obviously worsened and manifested in the domains of self-care and understanding and communicating as well. Though there are reports that the positive symptoms of schizophrenia become less severe or even diminish with aging, negative symptoms are more variable and do leave the person with related disabilities (Palmer et al., 1999). This state has been termed 'schizophrenia burn-out.' In confirmation with these reports the sample of the present study recorded higher disability. Affective disorders, especially Depression, have been reported to be associated with disability, functional decline and diminished quality of life, increasing demands on caregivers and service utilization (Charney et al., 2003). Elderly persons with bipolar disorder have also been reported to have generally less severe symptoms (Broadhead and Jacoby, 1990), more frequent and longer episodes and more rapid cycling (Cutler and Post, 1982) compared to younger persons which can affect their functional level. These do explain the higher level of disability among the PMI group of the present study. According to Cohen et al. (2000), some geriatric patients with schizophrenia may lose skills necessary to report symptoms, leading to the impression that their clinical status is improving but the trend among the elderly persons with schizophrenia appears to be of 'social adaptation' which strengthens the impression. This could be one of the reasons that the disability experienced by the elderly with chronic mental illness go unnoticed and hence their needs are not attended to. Disability status of elderly persons with chronic mental illness is also explained in terms of changing role expectations. The general expectations from the elderly, both by the family and community diminish as age advances, compared to younger adults. Patients who could not meet the challenges of young adulthood may have less difficulty in meeting the role expectations associated with later life, which are less challenging. However, despite this understanding, age related neurological contributions to disability in the elderly cannot be ignored. Argue that neurobiological changes associated with later life may foster a decrease in psychotic symptoms but functional disabilities can persist.

Quality of life of elderly persons with mental illness is also affected. The disability experienced takes its toll on the quality of life of these persons. Moreover, elderly persons with chronic mental illness from the rural areas had a poor quality of life compared to their urban counterpart. Physical domain and the environment domain seem to have contributed the most to the low average overall QOL, especially of those from rural area. The physical domain incorporates the facets of activities of daily living, dependence on medicinal and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work capacity. Environment domain includes the facets of financial resources, freedom, physical safety and security, health and social care facilities (accessibility and quality), home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment, and transport. Both these areas are of important consequences for day to day functioning. Persons with mental illness have difficulty in these facets of living and hence, experience poor QOL. In the Indian context, with age people tend to accept others as 'they are' and refrain from complaining, and may also develop a philosophical approach to life. This can explain to some extent the average QOL in the social relationship domain.

Compared to the CG, the PMI group experienced significantly poor quality of life. QOL in Physical, Psychological, and Environment domains were significantly poor indicating the impact of mental illness on the quality of life with both physical and psychological domains getting affected which in turn affects the environment domain. Higher disability among the mentally ill elderly group of the study sample may account for their poor quality of life. Age also has an impact on the QOL with higher age group experiencing further drop in their QOL, and physical and environment domain contributing to it. This again is in line with the finding of increase in the level of disability with further aging. Contribution of level of disability to quality of life is further confirmed by the finding that QOL was negatively associated with level of disability. Lower the disability higher was the quality of life, irrespective of domicile and age of the participant. Disabilities do restrict the functioning in different areas of life thus affecting the QOL. Patients with schizophrenia are reported to show more age related decline in cognitive functions than do age matched control subjects (Friedman et al., 2001; Jeste et al., 2003) affecting their daily functioning and in turn their QOL as revealed in the present study too.

The insights from this study suggest that disability should be considered as an important dimension of chronic mental illness which has a significant impact on the quality of life of elderly persons. We feel that this study is noteworthy as it explores the neglected area of elderly population recovering from severe and persistent mental illness. The results point towards the kind of problems of life encountered by this population. The findings are of relevance to the mental health care service providers and can serve as guide in planning mental health services including rehabilitation planning for the elderly population.

However, the findings are the result of a pilot study. The data pertains to only a limited geographical area in the state of Karnataka (India) and on a small sample. Moreover, random sampling could not be done and the investigators had to take all the available cases during the period of data collection. The sample was drawn from psychiatric clinics and not from community survey which limits the generalization of the findings. We study used standard tools of measurement and hence the possibility of losing culture specific information cannot be ruled out. In-depth interviews and the qualitative data may provide wealth of information in this regard. Further research and community survey on wider population of elderly people who have chronic mental illness is recommended

6. Conclusion

The study aimed to explore level of disability and quality of life of elderly persons diagnosed with chronic mental illness compared to their normal counterpart. Though the severity of symptoms reduces in most people with this illness and overt symptoms may not be observed, associated disabilities are present affecting the quality of life as demonstrated in this study. The study highlights the need for research and service provision for the elderly persons with chronic mental illness.

Conflict of interest statement

None.

Contributors

All the three authors were involved in the designing and planning of the study. Dharitri R was involved in the literature search and the preparation of the manuscript. Dharitri R and N S N Rao managed and supervised collection of data. N S N Rao did the statistical analysis of the data. Dharitri R interpreted the results and prepared the final draft of the manuscript. Kalyanasundaram provided critical analysis and co-edited the manuscript. All authors contributed to this paper and have approved the final manuscript.

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