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BURDEN OF MENTAL ILLNESS ON FAMILY MEMBERS, CARE-GIVERS AND THE COMMUNITY

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ABSTRACT

Objective: **To determine the burden of mental illness in the family/caregiver and the community.**

Design: **A cross-sectional descriptive study.**

Setting: **Rehabilitation centres, community day centres, resettlement villages and in the community in three provinces (Harare, Bulawayo and Masvingo), Zimbabwe.**

Subjects: **A sample size comprising sixty six care-givers and 126 patients were consecutively interviewed for the study.**

Results: **The care-givers had a mean ± s.d. age of 48.8 ±15.7 years. The majority were females (80.3%), married males, 76.9% (p=0.073), unemployed females, 94.3% (p=0.0004) and parents of the patients accounted for 51.5%. Many respondents believed that the cause of mental illness was witchcraft (31%), they experienced financial constraints (63.6%), and spent a lot of money on food (56.1%). Patients were younger than their caregivers, with a mean ± s.d. age of 37.7 ± 12.8 years and mostly on medications (91.3%).**

Conclusion: **The caregivers were mainly women and unemployed, whereas patients were mostly male. Caregivers were faced with multiple problems, but they were more tolerant to patients' behaviour than the community at large.**

INTRODUCTION

Care-givers of mentally ill patients encounter many problems in looking after them. A well planned community-based/ informal care is a good alternative to institutions/ formal care. It is assumed to be cheaper and allows for gradual integration of patients to the community(1). The community-based /informal care is the informal social networks that include those relationships or sets of relationships that are "existing" rather than "created", and that spontaneously occurs in the natural environment, such as family, friends, church and organisations not professionally financed(2,3). Because of decreased lengths of in-patient hospitalisations and increased emphasis on community-based programmes, much of the daily care of patients with mental illnesses falls to care-givers rather than mental health professionals(4). Life style disruptions that resulted from the mental illness(5) made caregivers' personal perception of the situation and the extent to which the person feels burdened(6) is increasingly great. Family members in Badger and Yarrow's studies(7,8) spoke of the stigma associated with mental illness and interpersonal difficulties within the family unit. Another common challenge among 27% of the care-givers related to the symptoms exhibited by individuals with the mental illness(4). Care-givers' burden such as emotional, social and financial stress that the illness imposes on the family has been widely documented in literature(4, 9-11). Besides, care-givers have cited multiple examples of difficulties with health care professionals relative to their lack of communication and lack of involvement in the treatment of their loved one(7,12). In spite of this, there is growing evidence that points to the benefits of involving relatives (or other informal carers) in treating people suffering from mental illness(13). This is because families commonly provide useful information about the patient and their illness. This can facilitate a treatment plan in which the family can play a prominent role in helping to supervise medication, encouraging participation in rehabilitation programmes. The study's rationale is to our knowledge the first of its kind in Zimbabwe. Thus, this paper reports on the burden of mental illness on the families/care-givers in the community in Zimbabwe.

MATERIALS AND METHODS

Sample and design: A sample comprised 66 care-givers and 126 patients. They were males and females, however, children were excluded from the interviews. Sampling ratios differed at three provinces due to the varying numbers of daily attendees. Thus, the average recruitment rate ranged from 30 to 40 or more in each province. They were consecutively recruited from psychiatric units, four rehabilitation centres, two community day cares and two resettlement villages in the three provinces (Harare, Bulawayo and Masvingo) in Zimbabwe. We used a convenient sample size. It was a cross sectional study. Informed consent was obtained from each patient and Shona was the language of the study. The permission to conduct the study was obtained from Medical Research Council of Zimbabwe (MRCZ) and the relevant authorities.

Instrumentation: Care-givers and patients were interviewed by a standardised designed questionnaire. Twelve focus group discussions were held with the community members in those provinces. The questionnaire consisted of a close-ended questions, such as to what extent have your family members been affected by the patient's illness? The questions covered socio-demographic characteristics, community perception and definition of mental illness, attitudes, problems faced, willingness to live with mentally ill, costs incurred, accessibility and availability of mental health services in the community.

Data analysis: We used descriptive statistics to analyse the data. Chi-squared statistics (with Yale's correction) and Fisher's exact tests (2-tailed p-value) were computed for categorical variables. The community responses were converted into quantitative data and analysed in percentages.

RESULTS

Characteristics of the participants: Sixty six care-givers were enrolled for the study. They had a mean ± s.d. age of 48.8 ± 15.7 years and were older than the patients. It can be seen in Table 1 that most of the respondents (81.8%) were aged 35+ years, female (80.3%), married male, 76.9% ($\chi2$= 5.24, df= 2, p=0.073) and unemployed female patients, 94.3 % ($\chi2$= 15, df=2, p=0.0004). Many male patients had a primary education (46.2%), Table 1. Parents of the patients accounted for 34 (51.5%); the remaining 14 (21.2%) were siblings, seven (10.6%) spouses, two (3.0%) uncles/aunts and others six (9. 1%). Figure 1 shows that many care-givers (36%) had no income.

Table 1

Sociodemographic distribution of the Care-givers

Variables	Male N=13 (%)	Female N= 53 (%)	$\chi2$	df	P-value
Age					
<35 years	3 (20.1)	11 (17.0)			1.00
35+	10 (79.9)	44 (83.0)			
Marital status					
Single	1 (7.7)	10 (18.9)	5.24	2	0.073*
Married	10 (76.9)	22 (41.5)			
Others	2 (15.4)	21 (39.6)			
Education					
Nil	3 (23.1)	18 (34.0)	0.85	2	0.653
Primary	6 (46.2)	24 (45.3)			
Secondary/ Higher	4 (30.7)	11 (20.7)			
Occupation					
Employed	2 (15.4)	2 (3.8)	15	2	0.0004#
Self employed	4 (30.8)	1 (1.9)			
Unemployed	7 (53.8)	50 (94.3)			

*P= 0.073; #P= 0.0004

Most of the patients (n=126) cared for by the care-givers were male, 83 (65.9%), on medications, 115 (91.3%) and sticking to their medications. Over one-third of them were hospitalised two or more times, 61 (48.8%), the remaining, 46 (36.8%) were admitted once and 18 (14.4%) never being admitted to any health institution. Thirty (45.5%) patients were normally employed and 36 (54.5%) unemployed before the start of their illnesses. Over half (57.6%) of the patients earned nothing, but they had accessibility to medicines either from hospitals (49.6%) or health centres/clinics (47.1%). Patients had a mean ± s.d. age of 37.7 ± 12.8 years, with a mean ± s.d. duration of illness of 12.9 ± 7.4 years. Over half (54.7%) of the patients were aged less than 30 years and mainly male patients ($\chi2$= 19.7, df=2, p=0.0001). They were often accompanied to health facilities by parents, 25 (39.7%), siblings, eight (12.7%), none, two (3.2%), spouse, four (6.3%), cousin, one (1.6%), and others, twenty three (36.5%).

Figure 1

Income brackets of caregivers

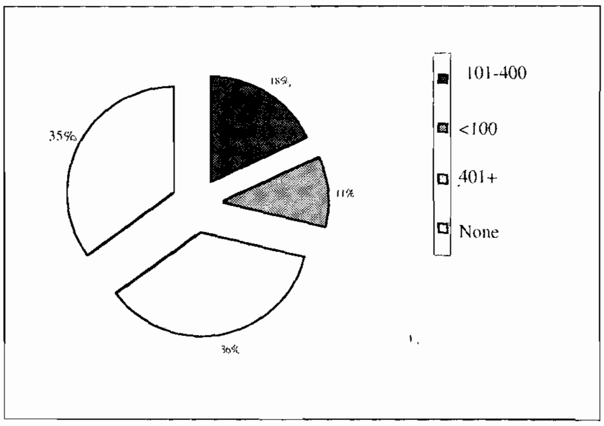
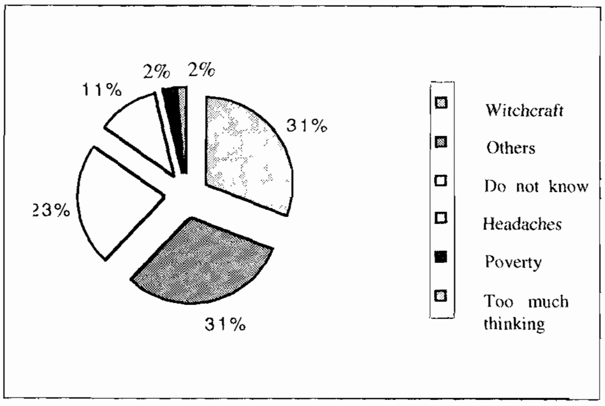


Figure 2

Pathways of health seeking behaviour



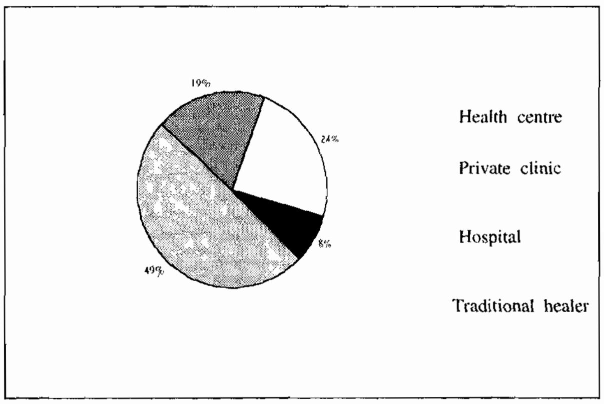
A care-givers' role and community perception: Average gross household monthly income for care-givers: many (36.4%) earned nothing, 10.6% earned less than Zim $100, and 34.8% earned Zim $101-400, that is, below the national poverty datum line. Other sources of earnings were selling of farm produce (24.2%), cottage industry (10.6%), none (50.0%) and others, (15.2%). The mean ± s.d. hospital costs were 11.7 ± 41.5 Zim dollars and 4.5 ±14.1 Zim dollars for transport. The mean ± s.d. time taking to reach the health facilities was 107.1 ± 83.8

minutes. Most of the care-givers, 50 (75.8%) did not incur any cost for hospitalised patients as mentally ill patients received free health services in Zimbabwe. This was during the period of the study. Most of the care-givers admitted that the pattern of patients' food intake had increased during the illness (84.8%). They said they could not provide supplementary feeding to their patients (10.6%). Forty two (63.6%) of the respondents had financial constraints and 27.3% claimed that living with mentally ill patients was impossible, because they tend to be violent and destroying property. Many respondents spent more than three hours looking after the patients (36.5%), the remaining spent one to two hours (24.2%), less than one hour (34.8%) and none (4.5%).

Accessibility to health facilities: Most respondents walked on foot to health facilities (74.2%), but others by bus (9.7%), private cars (4.8%) and other means (11.3%). Over half of the respondents covered a distance of 0-5 km (55%). Care-givers admitted that the patients' illness affected their daily activities, four (6.1%), everything in their life, seven (10.6%), farming, seven (10.6%), none, 47 (71.2%) and sewing, one (1.5%). Other causes incurred in looking after the patients were in form of food, 37 (56.1%), none, 19 (28.8%), and others, ten (15.2%). Though 75.8% of the care-givers claimed that they first sought help for their patients from biomedical facilities, about 73.2% of the patients admitted that a traditional healer first saw them. Many care-givers believed that the cause of mental illness was witchcraft, 31% and others, 31% (congenital, substance use/abuse, depression, injury).

Figure 3

Causes of mental disorders



Knowledge and attitudes about mental illness: Fifty three (80.3%) of care-givers admitted having knowledge about mental illness; and the source of their knowledge was natural (66.7%), taught at hospitals/clinics (13.6%), nil (4.5%) and other sources (15.2%). None use of rehabilitation centres: five (7.6%) of care-givers had no knowledge of existence of such facilities, two (3.0%) said patients were too ill to attend, eight (12.1%) patients were disinterested in the services provided, 15 (22.7%), said they were not worthwhile for patients to attend, and other reasons, 36 (54.5%). About one-third of the care-givers preferred to take their patients to hospital, 41 (49%) and followed by traditional healer, 16 (19%), Figure 3. The results of focus group discussions in the three provinces did not differ as for attitudes toward institutionalisation of mentally ill patients (26.3% in Bulawayo, 22.2 % in Harare and 20% in Masvingo). The communities at large were not tolerant to mentally ill patients as the care-givers who were more caring. They expressed distrust and fear of the mentally ill patients, because they were violent and dangerous (27.3%). Community members felt that the causes of mental illness were thinking too much, poverty, witchcraft, crust by ancestral spirits or from the god. Some members linked mental illness with violence, theft, drug abuse, divorce, depression and congenital disease. However, they suggested that the community could be helped in several forms; financial assistance, 30 (45.5%), food and clothing, four (6.1%), home-based care, 14 (21.2%), institutionalisation, 15 (22.7%) and rehabilitation 3 (4.5%).

DISCUSSION

Many community members (31%) believed that mental illness was caused by witchcraft. This belief exists in most African cultures; for instance, anxiety is expressed as fears of failure in procreation, in dreams and complaints about witchcraft(14). Though the first care-giver consulted was a biomedical provider in the current study (75.8%) and in a previous study (80%) in Zimbabwe(15), the remainder sought help from traditional healers first. This may be attributed to the fact that over one-third (45.5%) of our care-givers either in or had primary school education that might have influenced pathways into care in this population (Figure 3). Generally, Zimbabweans are knowledgeable and appreciative of the fact that modern and traditional health cares complement each other. In the current, study the care-givers were a bit older, mean ± s.d. age was 48.8 ± 15.7 years, this agrees with the finding of Doornbos of 56.2 ± 10.2 years(4). Our observation is that most of the care-givers were married (76.9%) and parents (51.5%) to the patients, whereas most patients were male (65.9%) and sticking to their medications (91.3%) a similar observation has been made elsewhere(4), (76.9%, 51.5%, 65.9% and 91.3% respectively). However, our finding's figures were a bit lower which may reflect a broad definition of mental illness in developed countries' community versus Zimbabwean community with a higher rate of cases' reporting and diagnosis. A widespread belief in our community is that mentally ill patients were violent and aggressive (27.3%). This is in agreement with a previous study (42%) in the community where they perceived the mentally ill patients as aggressive and dangerous(16). This can be explained by the fact that sadly in Zimbabwe, trained community psychiatric nurses in district hospitals are tasked to other duties (for example to serve in surgical or obstetrics and gynaecological units) rather than to offer psychiatric services in the hospitals or in the community. This might have a negative influence in community knowledge and attitudes toward mentally ill patients. Several studies concur with the current study in that caregivers faced by financial constraints (4,9), stigma (7,8), distressed by aversive patient's behaviour (17) and life style disruptions resulted from the mental illness (3).

Focus group discussions have generated many important implications for this study. First, discharging patients from psychiatric units/hospitals to community that lacks the rehabilitation's facilities for daytime shelter and occupation may be a change for the worse. Secondly, the African system of extended family has tremendously disintegrated by the prevailing economic hardships. Consequently, the participation of the family in mental health care has undergone many changes through years. For instance, the dissatisfaction of caregivers in community settings may jeopardise provision of quality mental health care in the community.

It is therefore a high time that systematic efforts should be made to recruit, train, and place village workers in community to help in promotion of mental health care. This approach can work very well, because most individuals with mental illness are familiar family members and neighbours whom they can easily integrate into such activities in any community(18). Thus, multi-disciplinary groups such as non-governmental organisation (NGOs), community psychiatric nurses, village community workers and caregivers to work on mental health care aiming at improvement of care system and above all to lobby for changes is essential for better care for mentally ill patients. We therefore conclude that exposure and health educating the community on mental illness are very important. This could lead to acceptance of psychiatric patients and removal of the stigma on mental illness in the community, if the necessary infrastructure and support are made available to the caregivers. The shortcoming of this study is firstly we do not explore to whether or not the types and severity of psychiatric disorders having remarkable impact on caregivers and secondly what copying mechanisms have they adopted to deal with these types of problems.

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