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A little knowledge: Caregiver burden in schizophrenia in Malawi

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Abstract *Objective* To determine the relationship between schizophrenia knowledge and burden of care among caregivers of people with schizophrenia in Mzuzu, Malawi. *Method* We recruited 90 patients and 90 caregivers to a randomized, controlled trial of group caregiver education in schizophrenia. At baseline, we administered the Family Questionnaire, which measures caregivers' knowledge of biomedical and psychosocial aspects of schizophrenia. We measured caregiver burden with the Involvement Evaluation Questionnaire. Using multivariate analysis, we examined the relationship between knowledge and burden, controlling for other patient and caregiver variables. We hypothesised that knowledge and burden would be inversely related. *Results* Caregiver burden was associated with knowledge ($p = 0.001$), but contrary to our hypothesis, greater knowledge was associated with greater burden. *Conclusion* In this population, knowledge about schizophrenia was associated with higher caregiver burden. This does not prove that knowledge causes burden, but suggests that cultural factors may mediate the relationship between knowledge and burden, and that care is

needed when introducing caregiver education in new cultures.

Key words schizophrenia – caregivers – burden of illness – transcultural psychiatry

Introduction

Psychoeducation in schizophrenia has been shown to be effective in developed and emerging economies [5, 6, 16, 18, 22, 26] and has been recommended as standard care for patients and their caregivers [1]. The Cochrane review showed that psychoeducational interventions, including group caregiver education, led to reduced relapse rates for patients [22]. The potential benefits of group education for caregivers themselves include lower burden of care: the rationale for the intervention derives in part from the observation that caregivers' knowledge of schizophrenia and other psychoses correlates negatively with burden [6, 16, 27].

In 2005, we began a randomised, controlled trial (RCT) of group caregiver education in schizophrenia in Mzuzu, Malawi [7]. Among the principal objectives of the RCT is to evaluate the effect of knowledge acquisition on caregiver burden. Before delivering the intervention, we measured caregivers' knowledge and burden, to determine whether the two were related at baseline. In keeping with previously published studies, we hypothesized that knowledge and burden would be inversely related. Additionally, we aimed to identify other clinical correlates of knowledge and burden.

Method

Study setting and participants

The study setting was St John of God Community Mental Health Services (SJOG) in Mzuzu, Malawi. Mzuzu is the largest town in Malawi's northern region, with a population of over 100,000. Most

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Mzuzu residents understand spoken English, and all residents speak Tumbuka, which is the main language in the northern region. There is no distinction in Tumbuka between schizophrenia and other forms of mental illness. Mental or behavioural problems that are recent in onset and considered to be medical or treatable are called *kuzweta mutu*, which translates as ‘confusion of the head’. People with chronic or intractable mental or behavioural problems are sometimes called *wakufuntha*, a label that carries with it a sense that there is no hope for recovery, and that either witchcraft or drug abuse is responsible for the illness. Traditional beliefs attributing sickness, death and other unwelcome events to witchcraft are widely held in Malawi. Bewitchment is considered the cause of many types of illness, including mental illness, and traditional healers are frequently consulted [17, 31, 35].

At the time of the present baseline analysis, we had invited 109 patients and caregivers to participate in an RCT of group caregiver education in schizophrenia. All 109 patients agreed to take part, but 11 caregivers refused consent when first approached, and 8 caregivers later withdrew consent before their baseline assessments were completed. Thus the 90 patients and caregivers discussed here are the first 90 patient-caregiver pairs to consent to participate. In the event that more than one caregiver consented per patient, the caregiver paired with the patient for analysis was the key caregiver, defined as he or she who had most contact with the patient in the previous four weeks. We received ethical approval from the National Health Sciences Research Committee, Lilongwe and the Ethics Committee of the Hospital Order of St John of God, Dublin. We obtained written informed consent from each patient and caregiver.

■ Assessments

The measure of caregiver knowledge of schizophrenia was the Family Questionnaire (FQ) [5]. This self-report instrument, with a range of 0–84, assesses an individual’s knowledge of six biomedical and psychosocial aspects of schizophrenia: risk factors, symptoms, recovery, medication, hospital treatment, and caregiver support. We measured caregiver burden and documented demographics with the Involvement Evaluation Questionnaire (IEQ) [33]. The IEQ, which is also self-report, comprises four subscales: supervision, worrying, tension and urging. In order to obtain a score for supervision or urging, and hence a total score, the caregiver must have spent more than one hour per week with the patient in the previous four weeks (IEQ, Q.15). The range is 0–108.

Patient assessments were: diagnoses, duration of illness, demographics and functioning with the Structured Clinical Interview for DSM-IV-TR (SCID) and the Global Assessment of Functioning (GAF), which is Axis V of the SCID [10]; schizophrenic symptoms with the Scale for the Assessment of Negative Symptoms (SANS) [2] and the Scale for the Assessment of Positive Symptoms (SAPS) [3]; and insight with the Schedule for the Assessment of Insight (SAI) [9]. The SAI comprises three subscales: treatment adherence, recognition of illness, and symptom relabelling.

All instruments were independently translated from English to Tumbuka by two researchers and four colleagues from SJOG. Our four colleagues were all native Tumbuka speakers, and bilingual, and each was from a dialectically distinct district of the northern region. A consensus meeting was held at which final definitive translations were agreed. Inter-rater reliability ($\kappa > 0.8$) was achieved for all observer-rated instruments after translation. We have previously published patient data obtained using the Tumbuka versions of the SCID, GAF, SANS, SAPS and SAI [7].

■ Data Analysis

We used univariate analysis to identify unadjusted correlates of FQ and IEQ scores. The caregiver variables that underwent univariate analysis were age, gender, educational level, relationship with the patient (whether or not the caregiver was a parent or spouse), weekly contact with the patient (± 32 h), and the number of people in the household. The patient variables ana-

lysed were age, gender, educational level, duration of illness, location of first treatment for psychosis (conventional or traditional medicine), number of psychiatric hospitalisations in the previous 2 years, lifetime alcohol or substance misuse, SANS, SAPS, GAF, SAI total and the SAI subscales: treatment adherence, recognition of illness, and symptom relabelling.

We entered unadjusted correlates of FQ and IEQ (trend level or stronger; $P \leq 0.10$) into linear multiple regression models, with FQ and IEQ as dependent variables. We added caregiver variables first, followed by patient variables. We reported on R, R^2 change, and the *beta* coefficient. R represents the cumulative contribution of all independent variables in the model to the dependent variable. R^2 change, which is reported for each independent variable, indicates the strength of the correlation between that variable and the dependent variable; the range of R^2 change is 0.0–1.0, and the closer it is to 1.0, the stronger the correlation. The *beta* coefficient indicates the direction of each correlation.

Results

■ Characteristics of the sample

Characteristics of caregivers and patients are presented in Table 1. Seven caregivers (7.8%) reported patient contact of less than one hour per week and were excluded from further analyses. There were no other significant differences between these seven patient-caregiver pairs and the remaining 83.

■ Schizophrenia knowledge

The mean FQ score was 39.4 (SD = 12.7; median = 3.0). Knowledge correlated negatively with caregiver age ($R = 0.35$; *beta* = -0.35 ; R^2 change = 0.13, $P = 0.001$).

Table 1 Characteristics of caregivers and patients ($n = 90$)

Caregivers	
Age in years, mean (SD; range)	39.5 (13.7; 17–73)
Male gender, n (%)	41 (45.6)
Spouse or parent of the patient, n (%)	44 (48.9)
Education, secondary level or higher, n (%)	41 (45.6)
Number of people in household, mean (SD; range)	7.0 (2.8; 1–15)
Weekly contact with the patient, n (%):	
<1 h	7 (7.8)
1–32 h	23 (25.5)
>32 h	60 (66.7)
Patients	
Age in years, mean (SD; range)	33.2 (10.2; 17–65)
Male gender, n (%)	52 (57.8)
Duration of illness in years, mean (SD; range)	6.9 (5.3; 0.2–26.0)
Number of admissions to psychiatric hospital, mean (SD; range)	1.8 (1.6; 0–7)
Attended traditional / spiritual healer at onset, n (%)	38 (42.2)
SANS score, mean (SD; range)	3.3 (4.3; 0–18)
SAPS score, mean (SD; range)	2.9 (4.1; 0–15)
Lifetime alcohol or cannabis abuse or dependence, n (%)	23 (25.6)

■ Burden of care

The mean IEQ total score was 26.7 (SD = 22.6; median = 22.0). Three independent variables contributed to the model with IEQ as dependent variable ($R = 0.52$). IEQ score was positively associated with FQ score ($\beta = 0.30$; R^2 change = 0.13, $P = 0.001$), inversely related to the weekly duration of patient contact ($\beta = -0.33$; R^2 change = 0.09, $P = 0.01$), and inversely related to SAI symptom relabelling ($\beta = -0.22$; R^2 change = 0.05, $P = 0.03$). We repeated this regression analysis after excluding one outlier, a caregiver whose IEQ sumscore (103) was very high, especially relative to the caregiver's duration of patient contact (<4 h). The correlates of IEQ did not change in this analysis.

All subscales of the IEQ were associated with FQ total score, with the exception of the tension subscale. The only independent variable to correlate with tension was contact time, which was inversely related ($R = 0.25$; $\beta = -0.25$; R^2 change = 0.06, $P = 0.02$).

Discussion

This was an analysis of baseline data from an RCT of group caregiver education in schizophrenia in Malawi. The aim was to determine the relationship between schizophrenia knowledge and caregiver burden at the outset of the RCT.

■ Principal findings

Our principal finding was that caregiver burden correlated positively with schizophrenia knowledge: the greater the level of knowledge, the greater the level of burden. Higher burden also correlated with lower levels of weekly contact with the patient, and with impaired symptom relabelling on the part of patients.

■ Methodological considerations

The strengths of our study include the sample size, the use of acculturated standardised assessments, and the cultural uniqueness of the setting. Few studies have addressed the welfare of caregivers of people with mental illness in Africa [4, 20, 29], and this is the first to investigate the relationship between schizophrenia knowledge and burden.

There are a number of limitations to the study. The IEQ is an instrument developed and validated in the EU [33], and although we carefully translated it, we did not formally validate it in the Malawian setting. This lack of validation may partly account for our unexpectedly low IEQ scores, when compared to those found across Europe [28, 33]; authors elsewhere in the developing world found levels of burden similar to those in the developed world [15]. However, we

selected the IEQ as our measure because the components of caregiver burden it measures, supervision, worry, urging and tension, are universally recognizable. Additionally, although our scores were unexpectedly low, lack of validation alone does not explain our principal finding: that the relationship between burden and knowledge was the reverse of the expected relationship.

One potential explanation for low IEQ scores is under-reporting. Malawian caregivers may be reluctant to report subjective burden, which could be perceived as complaint or self-indulgence in a culture which highly values care of one's family. Alternatively, the burden of care may genuinely be lower in this population. Patients in the study were relatively well, as shown by the SANS and SAPS scores. Both positive and negative symptoms predict burden [23, 24, 28], and both were low among our patients. In fact, the lack of a relationship between symptoms and burden in this study could have been due to a floor effect. Family support may have reduced burden levels: the large household sizes relative to those in developed countries may distribute the burden of care among several family members, so that even the key caregiver does not have sole responsibility.

Our measure of knowledge, the FQ, has been used mostly in the UK and Ireland [5, 6, 19], but as a measure of biomedical and psychosocial knowledge, including knowledge of caregiver support, we considered it adequate and sufficiently applicable in this setting. FQ scores were low when compared with a recent Irish study with a similar sample size [19], but our caregivers were relatively uneducated, and knowledge was correlated with educational level. Additionally, FQ scores mirrored the poor community knowledge about the cause and nature of mental illness found in the Nigerian household survey [13].

We measured local beliefs about illness only by asking whether patients attended traditional or conventional medicine at onset. Our study would have been improved had we included a question that dealt specifically with traditionally accepted causes of mental illness, as in the Nigerian study [13], or had we elicited explanatory models of mental illness, as described in the RCT of family education in Vellore, India [8].

A further limitation is the sampling. An epidemiological sample may have given a truer picture of knowledge and burden among caregivers in the community. Caregivers participating in an RCT of psychoeducation may differ from other caregivers in important respects, including their levels of knowledge and burden. Also, our population was urban, while the majority of Malawians live in rural areas; studies elsewhere in sub-Saharan Africa suggest that exposure to biomedical models of mental illness is lower among rural caregivers than urban caregivers [25].

■ Knowledge and burden

Our finding that greater knowledge was associated with greater burden was unexpected. There are no definitive studies of knowledge and burden in schizophrenia in any setting, but other studies have reported either an inverse relationship [6, 16], or an equivocal relationship [14]. However, studies in other chronic disorders suggest that caregiver knowledge can have negative associations. Spitznagel [30] reported that dementia knowledge correlated with the desire to institutionalise, while Graham [12] found that dementia knowledge was associated with higher anxiety. It is possible that higher levels of knowledge are associated with higher levels of stigma, and stigma has been reported to contribute to burden among caregivers of mentally ill patients in Africa [29].

We tested whether the correlation between knowledge and burden was mediated by patient contact: more contact might lead simultaneously to greater knowledge and greater burden. In this too, we found the opposite to our expectation, as less contact time correlated with greater burden. The direction of causality here is not clear. Although we may assume that more contact leads to greater burden, the fact that a caregiver spends more time with a patient may indicate that the patient is not considered a source of burden. In the IEQ, the caregiver-patient relationship is measured mainly by the tension subscale, and more contact time was the only correlate we found of lower tension. Equally, time caregivers and patients spend together may improve relationships: a recent Nigerian study of caregivers in schizophrenia and affective disorders reported, “there was an impression that caring had made family emotional ties closer” (21).

Lower burden predicted by better symptom relabelling suggests that patients who recognise their own psychotic symptoms are able to self-monitor, which reduces the need for monitoring by caregivers. We previously found that better symptom relabelling was independently associated with better patient functioning [7], and better functioning would be expected to correlate with lower burden, but in this instance the relationship between burden and symptom relabelling persisted after controlling for functioning.

With respect to our principal finding, we suspect that cultural beliefs are important. In a Malawian population, it is arguable that caregivers who have little biomedical or psychosocial knowledge about schizophrenia are more likely than those with higher levels of knowledge to have traditional beliefs about mental illness. These include the beliefs, in keeping with the label of *wakufuntha*, that mental illness is caused by bewitchment or drug abuse [13, 17, 21]. Believing bewitchment or drug abuse to be the cause of illness may lessen the responsibility on caregivers for recovery. If bewitchment is thought to be the cause, there is little hope, and recovery is only possible if an external agent—the person unknown

responsible for bewitchment—acts. If drug abuse is thought to be the cause, patients may be inappropriately blamed for their own illness, so empathy and support may be lacking [13]. When a person is thought to be medically sick, however, as in *kuzweta mutu*, recovery is internally driven, and responsibility for recovery is assumed by caregivers. Although a Malawian caregiver who subscribes to the biomedical model of mental illness may appear more burdened than the caregiver who does not, high burden may reflect caregivers’ recognition of their role in recovery, and may paradoxically be in the best interests of those for whom they care.

Finally, is a little knowledge a dangerous thing? Should we abandon caregiver education in Malawi? Not yet. Firstly, this was a cross-sectional study, and our findings cannot show that schizophrenia knowledge causes burden. Secondly, previous studies of psychoeducation have shown benefits to caregivers other than those attributable directly to knowledge gain [18, 22, 34], including a reduction of burden in a study conducted in the developing world [14]. Nonetheless, caution is warranted. Caregiver burden is associated with poor quality of life [11] and psychological and physical morbidity [15, 32]. Only the results of the ongoing RCT will determine whether the introduction of caregiver education to Malawi is appropriate.

Conclusions

Greater knowledge about schizophrenia correlates with greater burden among Malawian caregivers; this relationship may be culturally mediated. Our findings do not prove that knowledge causes caregiver burden, but they suggest that careful evaluation is needed when introducing caregiver education into new cultures.

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