ILLNESS MODELS OF RELATIVES OF AFRICAN PSYCHIATRIC PATIENTS: IMPLICATIONS FOR A FAMILY-BASED SERVICE

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ABSTRACT

This study explores the illness models and service requests of relatives of 30 African psychiatric patients. Relatives’ perceptions of illness and expressed needs were elicited with a view to developing a more contextual understanding of disorder, and to obtaining an indication of interest in family-based services. The sample was selected from relatives who visited patients at the hospital over a 3 month period. Face-to-face interviews of approximately an hour in duration were conducted. Results indicated that relatives held a variety of explanatory models to understand their family members’ conditions. Although many of their beliefs were at variance with the biomedical model of illness, they nevertheless overwhelmingly supported the notion of the establishment of family-based services within the existing health care system. Implications for strategies of clinical care, as well as theoretical implications are discussed.
INTRODUCTION

This exploratory study was undertaken as the initial stage of an inquiry into service requirements of relatives of African psychiatric patients attending Valkenberg Hospital (VH), a major psychiatric hospital in Cape Town. The study elicits illness models of the relatives together with their perception of their own needs to make recommendations for the development of appropriate family-based services.

The introduction will first review the literature on family intervention with relatives of psychiatric patients and will address the contextual basis of this research. This will lead into a focus on the need to recontextualise psychiatric practice, paying attention as well to the dangers of recontextualised approach. The section that follows will look at adopting a strategy for cross-cultural practice, and the final section will address the aims of this study.

Research on family intervention with relatives of psychiatric patients

The role of the family in the epigenesis of mental illness is an area of continued research and debate. Most studies have looked at the detrimental effects of families on schizophrenic patients (Brown et al, 1972; Vaughn & Leff, 1976; Doane et al, 1981, 1985; Snyder & Liberman, 1981; Falloon & Penderson, 1985; Goldstein 1987). Much of this research has been done in the context of a vulnerability-stress model (Zubin & Spring, 1977; Stierlin et al, 1983; Goldstein, 1987), with a trend towards discovering family processes that may predict relapse.

The variable of 'expressed emotion' (EE), which includes indices of overinvolvement, hostility and critical comments, has been highly correlated with the likelihood of relapse (Brown et al, 1972; Vaughn et al, 1984; Karno et al, 1987; Leff & Vaughn, 1985).

1. In this dissertation the word 'African' is used to denote the 'Black' category of the Population Registration Act (1950). For a brief discussion of the politics of 'racial' labels in South Africa, see Swartz, 1985.
More recently, with the trend towards deinstitutionalization, there has been a move towards examining the potentially constructive role of families in the treatment of psychiatric patients (Lamb & Oliphant, 1978; Holden & Lewine, 1982; Kuipers & Bebbington, 1985; Hatfield, 1987; Hatfield et al, 1987; Kantor et al, 1987; Smith & Birchwood, 1990). The literature has attempted to redress the negative stereotype of the family which underrates their capacity to act as rehabilitative agents.

A further area of recent documentation has been the negative effects of psychiatric patients on their families. Some of the issues that have been addressed are the financial burden; the disruption of family life and the strain on family relationships; individual health problems of a physical and psychological nature; and the limitations placed on the social life of the family (Lamb & Goertzel, 1977; Goldman, 1980; Bernheim, 1982; Willis, 1982; Gibbons et al, 1984; Gubman et al, 1987; Holden & Lewine, 1982; Noh & Turner, 1987).

The call for support, information, and skills to meet the needs of the supporting family, together with a recognition of the value of family intervention for the ill patient, has resulted in the implementation of a series of family-based intervention programmes. These have focussed primarily on families of schizophrenic patients. Educational input, family therapy and relatives' groups have been offered in conjunction with the patient's psychotropic medication. The effectiveness of these programmes has been well documented (Goldstein et al, 1978; Goldstein & Kopeiken, 1981; Falloon et al, 1982, 1984, 1985; Leff et al, 1982, 1989; Doane et al, 1986; Hogarty et al, 1986; Tarrrier et al, 1988).

Cozolino and Goldstein (1986) have commented that the success of the family intervention is closely tied to the needs, expectations and previously held theories of the participants. However, as Jenkins (in press) has expounded, current formulations seem to locate these differences in personality-based explanations (Brown et al, 1972: Hooley, 1987), while paying scant attention to differences in essentially cultural components. Jenkins (in press)
delineates some of these components as 'the ethnopsychology of emotion, communicative styles, psychodynamics, ethnomedicine, and kin relations and social support'.

Furthermore, the majority of studies that have been cited were conducted on relatives of middle class American and British origin. Restrictions on the generalizability of the results, owing to the cultural specificities of this population, have been addressed. For example, it has been noted that such family members are particularly active and assertive with access to good resources (Holden & Lewine, 1982).

More recently, attempts have been made to undertake comparative research, particularly examining the cross-cultural applicability of the EE construct (Day, 1982; Kottgen et al, 1984; Karno et al, 1987; Wig et al, 1987a, 1987b; Barrelet et al, 1988; Parker et al, 1988). Jenkins (in press), however, highlights the shortcomings of these studies by pointing to their focus on empirically testing behavioural responses while ignoring the meaning of these responses in the specified contexts. In her study on American relatives of Mexican descent (in press), she argues for a synthesis of empirical testing and a 'psychocultural analysis' of the observed behaviour. She achieves this in her paper by linking the families' social responses to the cultural meaning embodied in their construction of the self and emotion.

These recent attempts to provide a cross-cultural perspective to research focussing on relatives of psychiatric patients have arisen from a general need to recontextualise psychiatric practice. This will be addressed further in the following section.

**Recontextualising psychiatric practice**

All too often a Western psychiatric model is employed with little concern for its appropriateness. The theoretical perspective informing the nosological categories and treatment method is regarded as an empirically existing reality, rather than a social, political and cultural artifact (Kleinman, 1977). This ontological error, whereby observations are recorded as direct representations of reality, results in the reification of
mental illness. With the assumption that an empirical essence exists, the opportunity to provide alternative modes of explanation, which may hold greater coherency for the patient population, is effectively suppressed.

According to Kleinman (1987) the source of this shortcoming can be located in the lack of reflexiveness exercised by Western healers who practise in the disease model. The notion of disease is not regarded as an explanatory model, but it is rather viewed as the fundamental biological disturbance that exists to the exclusion of other realities. From this reductionistic perspective, the personal, social and cultural metaphor are ignored or regarded as epiphenomenal layers that need to be removed in order to reveal an underlying causal process.

Medical anthropologists have attempted to address the limitations of this model by the use of the concept of illness, which is viewed as the personal, social and cultural meaning that is signified by the phenomenon (Eisenberg, 1977; Helman, 1984). In this way the patient's symptoms are distress signals which are rendered intelligible through interpretation within the sociocultural and personal context.

The movement within Western psychiatry resulting from the introduction of the illness concept has been towards an increased awareness of cultural variables in the construction of the disturbance. However, the task that grew out of this movement was initially regarded as that of peeling away the confounding variables to expose the universal underlying disease. The view in which culture is regarded as a variable shaping pathoplastic features of disease has been dubbed 'old transcultural psychiatry' by Kleinman (1977). Within this school, the aim of cross cultural research is to establish comparative epidemiology that answers such questions as 'Is depression the same in Africa as in Western nations?'; 'Is there the same amount of depression in these African nations?' (Drennan, Levett & Swartz, in press).
Underlying these research questions is the fundamental commitment to a disease model in which core symptoms are ultimately knowable. As Swartz (1985) points out, this approach discourages a consideration of social relationships and their role in the construction of psychopathology; 'social and cultural factors can never go beyond the status of modifiers in this model' (p 68). Kleinman (1977) reiterates similar sentiments when he warns that the superimposing of a template over a heterogeneous population results in the omission of culturally diverse responses. In this way an accurate reflection of the phenomenological experience of distress is compromised.

In an attempt to confront these limitations a new paradigm has been put forward, which rests on the tenet that the effect of culture is all pervasive on numerous levels. Within this perspective ‘the illness is the disease’ (Obeyeskere, 1985, p 187) as culture and psychopathology are not separate phenomena exerting an influence on each other but are interdependent features of a socially constructed world. This approach, labelled by Kleinman (1977) as the ‘new cross cultural psychiatry’, advocates the necessity to situate the patient’s suffering in the cultural context that renders it intelligible. For Kleinman ‘culture fills the space between the immediate embodiment of sickness as a physiological process and its mediated (therefore meaning laden) experience as a human phenomena’ (p 27). From this perspective then, to strip the phenomenon of its cultural weighting is to demolish the entire phenomenon. The development of this approach thus exposes psychiatry itself as a cultural product, with recourse to biological explanations arising form urban industrialized Western cultural strands. The acknowledgement of context in the foundations of Western psychiatry has allowed the profession to move beyond the ethnocentric perspective of scientism that dominated its early development. Particularly in South Africa, a country with a heterogeneous population, where a large number of people may not identify with a traditionally Western biomedical approach to illness, the necessity for a recontextualised approach to mental health and psychiatric care is imperative. Not to do so would be to ignore the cultural differences that do exist. However, a culturally
sensitive approach cannot be adopted without an appreciation of the dangers that exist with its usage.

**Dangers of this approach**

An issue of particular sensitivity in South Africa is when context is taken into account but is reified into a cultural essence, requiring protection from outside influences. This 'pseudo relativism' has provided justification for apartheid policy for many years in this country. The view of mutually exclusive groups that need to be isolated and preserved has been used to legitimate a system of legally enforced discrimination (Swartz & Foster, 1984; Swartz, 1985; Nell, 1990; Seedat & Nell, 1990). The danger lies in the widespread tendency of theoreticians to collude with the state by accepting the labels that were laid down by the Population Registration Act of 1950 as indicators of true cultural differences rather than as fundamentally administrative tools arising out of a particular historical and political order (Swartz, 1986, 1987). This is not to argue that the labels were and are meaningless; they certainly offer a reality of a particular kind, however their cultural meaning arises essentially post-hoc out of the particular historical and political forces at play. Thus, at no point can a politically defined label be used in itself to explain any differences (Thornton, 1988).

Evidence of the reification of culture is apparent in theories that propose the existence of an inherent and unchanging African personality characteristic of a discrete group of people (Swartz, 1985, 1986; Spiegel & Boonzaier, 1988). Much of the cross cultural research in South Africa has been employed to unravel the mysteries of the 'African experience' which are viewed as static and presented as value-free.

The perpetuation of generalizations is particularly evident in works that take on an evolutionary flavour. The central tenet of these works is the hypothesis that the African people's belief systems are lower in the phylogenetic scale of development than the Western idea system. For example, Hammond-Tooke's (1974) postulation of a 'pre-
scientific’ world view and Cheetham and Griffiths’s (1982) description of the Nguni people’s preliterate thought system serves to reinforce ethnocentric perspectives whereby a belief in the differences is attributed to the group’s deficits in cognitive skills and linguistic tools.

Similarly, healing practices have been hierarchically ranked, as evidenced by Schoeman (1989), who calls first for indigenous healing practices to treat spirit possession, but suggests that Western methods are indicated if traditional treatment fails. This implicitly constructs a hierarchy in which traditional healing is judged to be more acceptable, but less powerful than Western biomedicine.

Possibly equally as problematic is the stereotyping that proposes a fully integrated world view in which Africans are cast in harmony with themselves (i.e. living closer to their unconscious), their family and ancestors (e.g. Bührmann, 1977; 1979; 1982). Concomitant with this approach is the uncritical praise offered to indigenous healers who are seen to embrace the ‘holism’ of the African world view, and thereby extend beyond the limitations of Western healers. This romanticised perspective also erroneously perpetuates generalizations based on ‘cultural essence’.

The focus on culture as a mode of explanation for the differences that exist between people in South Africa also holds the danger of imposing a restrictive point of view that does not take account of external injustices but locates causal defects in the people themselves rather than in the structures of society (Mjoli, 1987; Seedat & Nell, 1990). In this way the discriminatory laws that impinge on the daily lives of the African people, creating a sense of powerlessness for individuals, are ignored, as is the oppressive material context. Pathology is linked to culture and issues such as oppression, poverty, the separation of families, and violence experienced on a daily basis are not addressed. Perhaps the error can be traced back again to the definitions of culture which tend to focus solely on such issues
as ancestor worship and allied beliefs and falsely extricate the people from the historical and political reality in which they are embedded.

Swartz (1990) highlights this problem in his critique of Gillis et al’s (1989) report on compliance with psychotropic medication on the part of African patients. He notes that in their explanations for poor compliance rates, the authors reproduce a belief that an impoverished material reality is nothing more than a ‘modifying factor’ (p 97), and that the reason for lack of compliance can be ascribed to a reified ‘African culture’. Swartz takes his critique one step further when he points out that the authors claim to speak for the patients and yet have made no attempt to elicit the patients’ views. The explanatory model of the patients provided by the authors seems to be reproduced from the authors’ conceptualisation of ‘African culture’. The tragedy, as Swartz states, is that ‘the emic "explanatory model" concept has rapidly become a form of ethnocentric "cultural diagnosis"’ (p 98).

Another issue that has been addressed by Gobodo (1990) is the danger of defocussing from individual dynamics and differences within each culture when taking account of the larger context in understanding the person. Thus the personal meaning of the patient’s experience of distress that arises from his/her interpretive activity requires attention. Ultimately it is the phenomenological experience shaped by social symbolism and interaction that provides the explicit text for distress.

Finally, there are implications in the relativist call to abandon attempts to convey meaning and make judgments of one context from the perspective of another. It can imply the need to abandon therapeutic interventions that have not grown directly out of the experience of the patient population. In South Africa this means that the role of traditional methods of healing may be seen to be more highly prized in the treatment of African patients than the services offered by the state. In this way justification is provided for the unequal
distribution of psychiatric services and the responsibility to provide sufficient and adequate services within the hospital system is abrogated.

**Adopting a strategy for intervention**

It is by abandoning the notion of cultures as mutually exclusive groups that need to be isolated and preserved that it becomes possible to contemplate cross cultural therapeutic practice. The issue of intervention can begin to be addressed if we move towards a perspective in which cultures are viewed as dynamic and diffuse, feeding into each other and transforming over time. From this perspective it is possible to adopt a strategy which combines systems and recognizes the benefits of negotiation between different explanatory models. Within this framework therapeutic practices can be used effectively across cultures without alienating the patient from the contextual meaning of the symptoms. Thus the true value of disease treatment can also be acknowledged, and furthermore, compliance, which is a key factor in the efficacy of this treatment, can be enhanced by negotiating illness interpretations.

Seedat and Nell (1990) refer to Bulhan's (1979, 1985) theory on the process of cultural transformation in the context of racial oppression. The third stage, described as the 'zone of contact, confrontation and mutual influence between dominant and dominated cultures' (p 144), and referred to as the 'zone of in betweenity', where each culture modifies the other, parallels the strategy of observing, joining and negotiating proposed in this research.

The fundamental principle which needs to guide this operation is one of effective negotiation whereby the process is not a prescriptive one involving the imposition of one culture on another, but rather a commitment to meeting the needs expressed by the patient population. In real terms this calls for a knowledge of the patients' experience and an understanding of their needs. It also requires a self-reflexiveness on the part of the clinician in order to achieve a satisfactory negotiation of explanatory models in the context of the clinical encounter.
In this way aspects of one culture can be modified and incorporated into another without abandoning a respect or consideration for the patient's viewpoint. As Gobodo (1990) writes, 'It is important first not to deny roots, and secondly not to become affixed on them, but to incorporate and grow with them' (p 97).

**Aims of this study**

Having argued for the need to contextualise psychiatric practice, and, furthermore, to do so by organizing care around the needs expressed by the participating population, the aim of this study was to elicit relatives' subjective appreciation of the illness experience and its particular psychological consequences for them. Furthermore, the study aimed to elicit their opinions on the notion of establishing family-based services. It was hoped that this information would be used to guide the implementation of services and would add to a process whereby different explanatory models are acknowledged and, parts of these models, negotiated.

**METHOD**

**Subjects**

Relatives of 30 African psychiatric patients admitted to Ward P12 at VH were interviewed when they attended the hospital to visit their ill family member. The interviews were conducted a few months prior to the desegregation by race of the closed wards at VH. Ward P12 was a 50-bedded African male closed ward at the hospital. It served as an admissions ward for psychotic patients, who often entered the ward in a florid state. Most referrals came via the day hospitals and the psychiatric emergency unit at Groote Schuur Hospital, a general hospital. Alternatively, patients were brought in directly by their families or the South African Police. Patients were usually transferred to another ward (P13) once their condition had stabilised; thus most patients in the ward remained unsettled. The duration of stay fluctuated between a week and a few months, with the
exception of one patient, who was kept for over a year. With the exception of this patient, the mean length of stay was $8^{1/2}$ weeks.

Table 1 presents the patients' diagnoses written in their folder summaries on discharge.

The dominant mode of treatment was psychotropic medication for the patient. Staff maintained little contact with the family besides occasional interviews that were conducted in order to obtain collateral information on the patient's illness.

Table 1

<table>
<thead>
<tr>
<th>Patients' Diagnoses on Present Admission to Hospital</th>
<th>No. of Patients (n=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia or</td>
<td></td>
</tr>
<tr>
<td>Schizophreniform Disorder</td>
<td>11</td>
</tr>
<tr>
<td>Epilepsy + Schizophrenia</td>
<td>2</td>
</tr>
<tr>
<td>Epilepsy + Mental Retardation</td>
<td>3</td>
</tr>
<tr>
<td>Toxic Psychosis$^a$</td>
<td>3</td>
</tr>
<tr>
<td>Organic Mood Disorder$^b$</td>
<td>1</td>
</tr>
<tr>
<td>Toxic Psychosis/</td>
<td></td>
</tr>
<tr>
<td>Schizophreniform Disorder$^{ac}$</td>
<td>2</td>
</tr>
<tr>
<td>Bipolar Affective Disorder</td>
<td>6</td>
</tr>
<tr>
<td>Alcohol Dementia</td>
<td>1</td>
</tr>
<tr>
<td>Organic Hallucinosis with Alcohol</td>
<td></td>
</tr>
<tr>
<td>Dependence and Withdrawal</td>
<td>1</td>
</tr>
</tbody>
</table>

$^a$ The toxicity was related to cannabis or cannabis and methaqualone.

$^b$ The OMD was similarly seen as related to cannabis abuse.

$^c$ These patients were left with a differential diagnosis.
In general, one relative was interviewed by the author, but when more family members were present, they were included in the interview. On four occasions 2 relatives were interviewed and on one occasion 3 relatives were interviewed. The responses elicited from the relatives in each of these four interviews was used in a cumulative way, and combined to represent one point of view for each interview. Seventy-eight percent (n=28) of relatives lived in the same home as the patient prior to his admission.

The sample was selected from the visitors present during visiting hours two or three times a week over a 3 month period from May to July 1990. Visitors who were relatives of patients were requested to participate in an interview. If more than one group of relatives were present in an afternoon, the visitors who arrived first were interviewed. It is possible that as these relatives were visiting their family members, they may have specific characteristics not shared by the total relative population. This will be addressed further in the discussion of results.

All relatives who were approached offered their assistance. The following relatives were interviewed: 9 mothers, 5 fathers, 3 wives, 5 brothers, 4 sisters, 6 first cousins, 1 grandfather, 1 brother-in-law and 2 uncles.

**Procedure of data collection**

The methodological approach was an in-depth qualitative and quantitative analysis involving face-to-face interviews of approximately an hour in duration. Relatives were approached in the visitor’s section of the ward and informed that a study was being conducted to establish the service requirements of families of psychiatric patients. They were interviewed by the author in a separate room once they had been assured of confidentiality and consent had been obtained. Most interviews were conducted in Xhosa. Since the interviewer was not able to communicate in Xhosa, a trained nursing sister, who has worked for 10 years as an interpreter for the Clinical Psychiatry Unit of the Medical Research Council, was
employed. She was conversant with the aims of the study, and, in order to minimize problems related to the interpretation of questions, she met with the interviewer prior to the data collection to discuss the meaning of the questions and the use of standard translations for phrases. Furthermore, a back translation was undertaken to ensure reliability (Brislin, 1986). There were no problems with the items as translated.

The interview

The interview schedule combined closed and open-ended questions, consisting of 49 items in total (Appendix A).

The first section addressed the demographic characteristics of the relative and the patient. Questions focused on identifying data of the relative and patient; the relative's psychiatric history; family history of psychiatric illness; course of the patient's illness in terms of number of admissions to a psychiatric hospital, age at first onset and age at first admission; composition of the household; and their financial situation in terms of sources of income.

The middle section covered the relatives' explanatory models of illness, which included the phenomenology of the illness particularly in relation to the behaviour that had led to the patient's admission to hospital; label(s) for the condition; aetiology and course of the illness; their perspective of the illness history; and the attempts they have made to cope with it in the past. This section was based on questions developed by Kleinman (1980) for eliciting the details of explanatory models. Further questions were included to obtain additional information on the basis of five categories outlined by Kleinman (1980) as the major concerns of explanatory models i.e. (a) aetiology, (b) time and mode of onset of symptoms, (c) pathophysiology, (d) course of sickness; and (e) treatment.

The following section of the interview focused on the needs of the family and problems that they might have experienced, and provided relatives with the opportunity to suggest services that would be beneficial to them. Specifically, they were asked to comment on the
appropriateness of educational programmes, individual support, contact with other families, and family therapy for themselves and their families. These possibilities were proposed on the basis that they have proved effective modes of intervention in previous studies in other countries (Goldstein et al, 1978; Goldstein & Kopeiken, 1981; Falloon et al, 1982, 1985; Leff et al, 1982, 1989; Doane et al, 1986; Hogarty et al, 1986; Tarrier et al, 1988).

Concluding questions addressed possible dates, times and venues for the implementation of family-based services.

RESULTS

The results of this study are presented in sections outlining: (a) the demographic and identifying characteristics of the relatives and patients, as well as some details concerning the composition and financial status of the household; (b) the explanatory models of the relatives in terms of their phenomenology of the illness, labels for the condition, aetiology, prognosis, and illness history; with a focus in the latter category on early signs of illness, advice received, patterns of health seeking behaviour, present admission to hospital and success of treatment; (c) their expressed needs, which includes their problems and fears together with their requests for family-based services; and finally, the results are concluded with (d) an in-depth qualitative account of one interview presented as an illustration in the format of a case study. Information obtained on practical arrangements was handed over to the hospital staff and will not be presented here.

Identifying and demographic characteristics

Table 2 summarises the basic identifying and demographic characteristics of the patients and relatives, including their age, educational status and their level of employment.
Table 2

Identifying and Demographic Characteristics of Relatives and Patients

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>18-43</td>
<td>20-72</td>
</tr>
<tr>
<td>Median</td>
<td>26</td>
<td>42</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0-Std 10</td>
<td>0-university</td>
</tr>
<tr>
<td>Mean &amp; Median</td>
<td>Std 3</td>
<td>Std 5</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>(6^b)</td>
<td></td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Semi-skilled</td>
<td>7%</td>
<td>11%</td>
</tr>
<tr>
<td>Unskilled</td>
<td>30%</td>
<td>39%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>23%(^c)</td>
<td>33%</td>
</tr>
<tr>
<td>Students</td>
<td>20%</td>
<td>8.5%</td>
</tr>
<tr>
<td>On Grant</td>
<td>20%</td>
<td>8.5%</td>
</tr>
</tbody>
</table>

\(^a\) This information was not elicited from relatives.
\(^b\) Married patients had between one and six children; single patients were reported to have none.
\(^c\) Unemployed patients had not worked for a mean of 3.5 years.

In addition, it was established that a mean number of 6.5 people were reported to be living in the patient's household. On average, each household had 1.7 people employed. Twenty-seven percent (\(n=8\)) of the households were receiving grants. In the households where no-one was employed, financial assistance was obtained from a family member living outside of the home in four cases and grants were received in two cases.
As far as previous psychiatric history of the patient was concerned, it was the first admission for 50% (n=15), while those patients that had been admitted before averaged three previous admissions. Relatives reported onset of the illness to be in the same year as the patient’s first admission to hospital in 73% (n=22) of the cases. In 5 of the 8 cases where onset predated admission, the onset was identified as having occurred before 12 years of age, with the admission only taking place in adulthood. The mean age for onset was 22 years, and the mean age at first admission was 25 years.

Although a family history of psychiatric illness was reported in 43% (n=13) of the patients, 92% (n=33) of the relatives denied any personal psychiatric history. Of the remaining 3, one relative reported a history of manic episodes, another reported epilepsy, and a third said that she had been in a state of *thwasa*² prior to becoming a traditional healer.

**Explanatory models**

As relatives of 30 patients were interviewed, the figures in this section refer to frequencies from a total of 30.

**Phenomenology of the illness**

Relatives’ descriptions of the illness, particularly those behaviours which they felt were responsible for the patient’s admission, most commonly focussed on aggressive and violent behaviour (n=18). Relatives of 11 patients noted that the patient had attempted to do damage to property, usually the household furniture; relatives of 9 patients remarked that the patient had attempted to assault people and on occasion pointed out that the attacks

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² *Thwasa* is a condition whereby the person is called on by ancestors, who appear in the form of spirits, to undergo the process of becoming a healer. The word literally means the emergence of something new, and is said to refer to the development of a new potential in the person (Bührmann, 1982). The person who is *thwasa* can be emotionally affected to a greater or lesser degree, and commonly hears voices, sees visions, is socially disruptive and is disturbed by dreams that interfere with sleep (Bührmann, 1982, 1984). The condition is believed to be exacerbated by delaying the prescribed rituals and training. However, once this has been completed, which can take many years, the person is considered able to understand the messages of the ancestors as conveyed in dreams, visions, illnesses and other misfortunes.
were directed at children or women: 'the children are scared because he throws stones at them', 'he even tried to assault a woman'. The fact that 2 patients had killed an animal and 2 patients had stolen was regarded by their relatives as evidence of their illness.

Another common response (n=9) was the reference to auditory and occasionally visual (n=2) hallucinations. Relatives frequently said 'he is hearing voices' and often added that he was talking incoherently (n=7) with such descriptions as 'he started talking nonsense', 'he was quiet, then all of a sudden he started talking rubbish to no-one', 'he spoke as if he was answering a question that no-one had asked'. Furthermore, relatives of 4 patients noted that he was disorientated: 'he didn't know who or where he was'.

Relatives placed emphasis on the fact that the patient was not sleeping adequately (n=8) and that he was restless (n=8): 'he started walking around all night', 'he sits up and talks through the night'. They also expressed their concern that he wandered away from home (n=2).

A number of relatives focussed on the patients' overactivity (n=8): 'he started jumping around, dancing, talking to himself and pointing to people in the street'. One relative described the patient's behaviour as 'excitable and euphoric', others commented that the patient talked considerably (n=5) and noted that he was preaching excessively (n=2).

Relatives of an equal number of patients (n=8) reported that the patient was particularly quiet and uncommunicative: 'he stopped talking to people', 'he was not answering questions', 'he would sit for a day in silence'.

There was also some comment on trembling and seizures (n=6), which on all occasions were described as part of the illness rather than an aetiological factor: 'when he is sick he fits', '... he falls down hard and causes damage to his head'.

3. All quotations are verbatim presentations of the interpreter's translations of relatives' comments.
A number of relatives drew attention to the patient's incontinence (n=4) and one relative referred to her family member's poor personal hygiene: 'he was not bathing and when he was given new clothes he just put them on top of his old ones'.

Some relatives felt that the patient was not eating sufficiently (n=3): 'he does not remember that he has to eat', whereas another relative declared that the patient 'eats whatever he sees'.

Further reference was made to ungrounded fears (n=3); loss of concentration at school (n=3); running around naked (n=1), and believing falsely that he was a healer (n=1).

**Labels for the condition**

**Labels provided by others**

Relatives of almost half the patients (n=13) maintained that they had not received a label or explanation for the patient's condition. Relatives of 9 patients were reportedly informed that the patient had *amafufunyana*\(^4\) by traditional healers (n=6), a faith healer of the Zionist Church (n=1), which is an African church that practices pentecostal type ritual healing (cf West, 1975), and people in the community (n=3). On two occasions a traditional healer and elders claimed that the patient was in a state of *thwasa*. With the exception of one doctor, who had apparently labelled the illness as nerves, and another who had accounted for the condition by reference to a head injury, relatives denied receiving names or explanations for the condition from hospital staff.

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\(^4\) *Amafufunyana* has been reported since the 1920's (Edwards, 1983) and is believed to be caused by the person obliviously eating an *idlis*\(\text{\(1\)}}\), which is a refined mixture of herbs and ants collected from the graveyard where they are believed to have been eating the flesh of a corpse. In this way the spirit enters the stomach of the person, often causing considerable pain. The person typically becomes agitated and hears voices that speak from his/her stomach, often in an African language foreign to the person.
Relatives' labels

Six of the 13 labels provided by others corresponded with the relatives’ perceptions of the illness. The remaining 7 diagnoses that were rejected by the relatives were *amafufunyana* (n=6) and the head injury (n=1). In 4 of these cases, the relatives could not offer an alternative label, and relatives of another 6 patients, who reportedly had not received any information, felt that they could not label or explain the illness.

Relatives frequently indicated that the patient was mentally ill using the Xhosa word *phambana* (n=8); they explained ‘there is something wrong with his brain’, ‘he is mad’.

Other respondents (n=4) labelled the condition as nerves, and expounded ‘whenever he worries about something small he gets ill’, ‘his nerves have gone wrong’.

There were also suggestions (n=3) that the patient was *thwasa*. One relative explained ‘he has to prepare to be accepted as a traditional healer. His ancestors have communicated with him and told him that he is to be a healer’. Other relatives commented ‘he has visions and dreams and the ancestor will instruct him through the dreams’, ‘he needs the help of a traditional healer...Certain rituals need to be performed. His parents need to slaughter a goat for him and make a necklace of the skin and hair’.

Relatives of the same number of patients (n=3) responded that the patient had *amafufunyana*: ‘he has been given the sand in the graveyard to eat which has ants in it... I don’t know who gave it to him...I am not sure why he got this sickness in Cape Town as it is the sickness of the country’, ‘he has been given a potion to drink which speaks to him when it is inside his stomach’.

One relative labelled the condition as mental retardation and another suggested that it was a toxic reaction to cannabis abuse.
Aetiology

 Relatives of 11 patients were unable to provide aetiological explanations for the illness.

 A belief commonly expressed (n=5) was that the patient had been bewitched. In all cases relatives would not offer a suggestion of who might be bewitching him.

 Relatives of an equal number of patients (n=5) related the illness to rituals which had not been performed. One relative explained that the patient was suffering as he had not returned to the Transkei to give his father and grandfather a traditional burial. Frequently (n=3) the rituals were associated to the state of thwasa: 'he must return to the Transkei where he must perform the rituals of slaughtering a goat and drinking the beer. He will also have to wear traditional clothes and white beads'.

 Although only relatives of 3 patients referred to cannabis abuse as an aetiological factor, an equal number (n=3) noted that cannabis exacerbated their family member's illness.

 One relative offered her point of view that the illness was caused by too much deep thought: 'he keeps quiet and thinks too much'. This sentiment was echoed by a relative who suggested that the patient needed to concentrate on work to keep his mind from 'overthinking'.

 Other responses that were offered were stressful living conditions, such as overcrowding and parental strife (n=1); the patient's loneliness and lack of structure in his life (n=1); head injury caused by falling on his head when he has seizures (n=1); and the incitement that occurred when the patient attended church (n=1): 'all the dancing and jumping in the church with the uneducated people went to his head'.

 Relatives of most patients (n=27), when asked whether the patient could control his illness, did not hold the patient responsible in this way. Relatives of two patients felt that
the patient could alleviate the condition if he abstained from smoking cannabis and the relative of one believed that the patient could avoid illness by concentrating on his work.

Course of illness
Relatives of 11 patients were unable to comment on the severity or the predicted course of the illness. Two of these relatives responded that 'only the doctor knows'. Relatives of 9 patients conveyed their belief that the condition was not severe and that the course of illness would be short. Relatives of a further 4 patients felt that although the illness was severe, it could be rapidly cured with Western medication. A few relatives (n=2) suggested that while the illness would follow a protracted course, the patient would eventually recover. The remaining relatives (n=4) expressed their concern that the patient would never recover.

Illness history

Early signs of illness
Responses to when relatives had first noticed a problem or change in the patient’s behaviour, provided a range from 0 to 25 years prior to the present admission, with a mean of 7.2 years.

Most commonly described as the earliest sign of illness was the development of an amotivational style. Patients (n=5) reportedly 'sat and stared blankly ahead', 'stood still without passing words' and 'used to sleep for long hours'. Others (n=4) did not respond when spoken to, refused to eat (n=3), were failing at school (n=2), and one was neglecting his personal hygiene.

Relatives also pointed to the patient’s increased level of aggression and oppositional behaviour at the start of the illness. They reported attempted assaults (n=7) and damage to property (n=5), including an attempt to flood the house by leaving taps running. One relative described: 'He had always been an obedient and respectful son to his father, who
was the headman. He started refusing to go to school and said that he could not see the board. Everyone thought he was lazy, but when he started playing his hi-fi through the night they realised that he was not well. He then rode up and down on his bicycle and would not respond to anyone.

Other relatives focussed on an increase in the level of activity: 'he looked drunk and was very active'. Patients were described as 'restless' (n=5), with disturbed sleep (n=2). It was also noted that they began to talk incessantly (n=4), usually incoherently (n=3), and one patient was reported to have prayed excessively.

Furthermore, relatives of 2 patients noted that the onset of the illness was heralded by seizures.

**Advice received**

Relatives of most patients (n=23) could not recall receiving advice on where to seek treatment. Relatives of 2 patients recounted that the community had suggested they consult a faith healer, and another relative reported that members of the church insisted on accompanying the patient to a faith healer in the Transkei. Families of 2 patients were advised by members of the community to consult a traditional healer. On one occasion a herbalist had advised hospitalisation prior to his treatment, and on another occasion, according to the relative, nuns of the Roman Catholic Church had proposed that the patient be sent to ‘an institute of higher learning’.

**Methods of treatment used**

Relatives of 10 of the 15 of patients with recent onset of the illness, reported that the patient had been brought directly to a day clinic or the hospital without seeking alternative treatment. With the exception of these and 2 other patients, who had previous admissions, relatives noted that all patients had attempted to seek help elsewhere sometime during the course of their illness. Fourteen of the patients had consulted a traditional healer, 9 had
approached healers in the Apostolic, Zionist and Roman Catholic Churches, and 2 had purchased herbal medicines on the street corner. Seven of these patients had used a combination of Western medical treatment, consultation with traditional healers and visits to faith healers of the church at various stages in the courses of their illness. A further 9 had combined Western medication with one of these alternatives.

**Present admission to hospital**

Relatives reported that in 23 of the cases a family member took responsibility for admitting the patient to hospital. Most commonly the mother took the decision (n=6); almost as frequently, though, the father (n=5) or brother (n=5) was responsible. Other family members that admitted the patient were 2 wives, a sister, a cousin, an aunt and an uncle. On four occasions he was sent as a referral from a doctor or the hospital staff, and on three occasions the decision was taken by his employer. No patients in the group had been brought in by the police.

**Success of treatment**

Relatives of 17 patients maintained that the illness had not improved substantially with any form of treatment. Of the remaining 13 patients, 12 were reported to have responded to hospitalisation and/or Western medication, and one relative believed that the illness had improved remarkably with the prayers of a priest from the Apostolic Church. Relatives of 3 patients proposed that the patient could still benefit by consultation with a traditional healer and intended to arrange this on the patient's discharge from the hospital. One relative suggested that a combination of a traditional healer with the Western medication would be most effective.

**Needs of the family**

**Problems and fears**

When relatives were asked to comment on the problems the family have experienced in coping with the patient, and the fears that they may hold, they revealed their concern that
he may be of harm to others (n=13) or to himself (n=6): ‘we are afraid because there is no man in the house and feel that he can be dangerous’. Relatives feared that his aggressive behaviour would cause damage to property (n=4): ‘he has broken window panes, so I don’t know what he’ll break next’. One relative claimed that the patient was inclined to steal when ill.

Another problem highlighted was the patient’s constant need for care (n=9): ‘when he is sick he is like a small child who needs my attention’. This was often related to his tendency to wander away (n=8): ‘if we don’t watch him he goes off and his father has to look for him in the night’.

Other relatives maintained that they were most pressed by the financial strain (n=4). One mother commented ‘he gives away or spends his grant without contributing to the household expenses and then demands food’.

Relatives contended that the patient’s oppositional behaviour was problematic for the family (n=2): ‘he is very stubborn and does not want to listen’, and another relative claimed that the patient’s refusal to eat caused her distress. One wife focussed on her feelings related to her husband’s loss of libido: ‘I find it difficult to come to terms with it. It leaves me feeling worthless and frustrated. Then we start quarreling’.

For some relatives their concerns and fears were directly related to the patient’s state of ill-health. Relatives expressed their anguish at witnessing the patient’s deterioration (n=4): ‘It is painful to see him ill’, ‘I don’t know when he is going to get better’, ‘my fear is that he is going to die’. One relative voiced her concern that the rest of the family were going to be afflicted with the condition, which she considered to be amafufunyana.
Proposed family-based services

Relatives of 19 patients did not respond when asked to make suggestions for a service that would assist the family to cope with the patient. One relative commented 'it is for the hospital to decide on its services'. The most common request (n=7) was for financial assistance. Interestingly, one relative who appealed for money promptly voiced her fear that her request was excessive and became anxious that consequently the patient would be poisoned by the state. Relatives of 3 patients also suggested that advice on how to deal with the patient could be useful. One of these relatives recommended a home visit that would allow the health care professionals to interact with the elders and thereby facilitate an exchange of ideas. One relative indicated that she would appreciate support of any kind, but could not elaborate on this.

When family-based services were suggested, relatives responded extremely positively. All were in favour of a programme involving contact with other families; relatives of 28 patients requested education about the illness, with relatives of 6 patients asking specifically for advice on how to deal with the patient; 25 requested individual support with a therapist, and relatives of 10 patients felt their family could benefit by family therapy, this request always arising when a relative was aware of a focussed family problem. Results of the ratings in order of preference of these four options are presented in Table 3.
Table 3

Relatives' Ratings in Order of Preference of
Four Family-Based Services

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<td></td>
<td>1 Most</td>
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<tr>
<td>Education (n=30)</td>
<td>16</td>
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<tr>
<td>Support (n=30)</td>
<td>5</td>
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<tr>
<td>Contact (n=30)</td>
<td>7</td>
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<td>Therapy (n=30)</td>
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Case study

The relative interviewed was the patient's mother, Sana, 48 years, who has no formal education, and practises as a traditional healer. She has been divorced from her husband since 1980 and cohabits with a married man in Paarl. She reported no history of psychiatric illness, although she admitted to thwasa prior to becoming a healer.

The patient, John, is 20 years, single, and lives with his family at Mbekweni location in Paarl. This is his fifth admission to VH, where he has received numerous diagnoses and has proved to be a complex diagnostic problem.

Synopsis of John’s early years, schooling and occupational history

John was born and lived until the age of 10 years in Beaufort West. In accordance with his parents' divorce settlement in 1980, his mother was granted custody over him. However, John was left in the care of his father and his aunt in the Transkei, where he commenced
Sub A at 11 years. He was an average student, although he failed Std 2. He left school in Std 3 at age 16 to care for his aunt, who was dying.

After leaving school he tended to his aunt’s cattle until he came to live with his mother in March 1987, after his aunt’s death. He then worked on a building construction for two weeks before his first admission to VH. After absconding from hospital in July 1987, he worked for a plumbing company for a week before he was fired for ‘inappropriate behaviour’. A month later he found employment in a fish factory and worked until he was readmitted in November 1987. He has not worked since and receives a disability grant on psychiatric grounds.

Current household circumstances

His mother’s household includes his five siblings, ranging in age from five to 21 years. He is the second eldest from his mother’s second marriage. His two sisters closest in age to him have a Std 5 and 6 education and are currently unemployed. The three youngest children are still attending school. In addition, he has three older half-siblings, born to mother in a previous marriage, who live in the Transkei (n=2) and Queenstown (n=1). His four elder sibling and half-siblings all have children of their own; 6 of the 8 grandchildren are in the care of John’s mother.

Mother is financially supporting the household of six children and six grandchildren. The only assistance she receives is John’s disability grant.

According to Mother’s reports of the psychiatric history of the family, Father and Mother’s sister have also been thwasa and underwent the process of becoming healers themselves. Furthermore, John’s sister received treatment for amafufunyana in 1983 by a traditional healer, and Father’s sister has been treated for mental illness (phambana) at Fort Beaufort Hospital.
History of admissions to VH

John's first admission to VH occurred soon after he began exhibiting religious and manic behaviour in June 1987, at the age of 17 years. He was referred immediately from VH to a medical ward as he was found to be in acute renal failure. His physical condition was attributed to the toxicity of herbal medicines prescribed by healers of the Zionist Church, who were treating him for amafufunyana. After a month of dialysis he was referred back to VH where a diagnosis of Organic Affective Syndrome was made and he was placed on Chlorpromazine. He absconded, however, after five weeks and was lost to follow-up. He was readmitted in November 1987 from Paarl East Hospital and was diagnosed Toxic Psychosis induced by cannabis on this admission. The medication prescribed was Haloperidol and thereafter Chlorpromazine and Fluphenazine. In January, when he settled, he was discharged with follow-up at the local clinic, but readmitted in July 1988. He was diagnosed Bipolar Affective Disorder, treated with Chlorpromazine and Fluphenazine, and discharged a month later when the symptoms remitted. Within a few weeks he was admitted for the fourth time. Once again he was diagnosed Bipolar Affective Disorder, and he absconded after 6 weeks. Although he had been given courses of Haloperidol and Chlorpromazine 1100mg on this admission, his thoughts and behaviour had not altered.

On his present admission he settled initially after being placed on Fluphenazine and Chlorpromazine, but he experienced a relapse two weeks later. He remained floridly psychotic for 3 weeks and then settled again. While in the ward he attempted to circumcise himself and managed a circumferential laceration of the foreskin. The circumcision was completed at Groote Schuur Hospital.

Mother's explanatory model

Mother reported that the first signs of illness were noted when he returned from the Transkei at 16 years of age. According to her, he attended a Zionist Church service with his sister, where he stood up and began shouting and preaching. The following morning he
continued to pray and was still excitable; he would not sit still for any length of time and talked incessantly.

Healers of the Zionist Church, who believed that he had *amafufunyana*, prescribed herbal medicines which reportedly failed to have any effect. His sister then brought him in to VH where he was noted to be passing dark urine and, as mentioned earlier, was treated for acute renal failure in a medical ward.

Mother recounted that she was collecting herbs for her practice in Botswana at the time of his first admission and when she returned she wanted to discharge him from hospital and have him treated by a traditional healer. Hospital staff tried to obstruct this by attempting to invoke a court order stating that he was to be kept in a place of safety, that place being VH; however this never came to fruition as they could not obtain Mother's address. Since then, she has opposed all hospital admissions.

In fact, Mother reported that no-one in the family was responsible for his present admission, which occurred when he went to look for work at Groote Schuur Hospital. She reported that he was sent from there to VH for a work assessment as the social worker whom he had been in contact with at GSH knew that he was a past patient at VH. When he arrived at VH he was found to be in an agitated state and was admitted to the ward.

Mother described John's present behaviour as restless, and commented that he was walking up and down and singing hymns. She claimed that he needed little sleep and irritated others with his attention seeking behaviour and intrusiveness. An example of this behaviour which she provided was that he would say "I love you" to anyone passing by. She reported that on occasions he claimed that he was receiving messages from Jesus and was hearing
voices calling his name and bidding him to attend church. She also imparted that the voices had instructed him to slaughter a cow to prevent people drowning in the sea.

Mother labelled his condition as thwasa. She elaborated ‘the ancestors are acting upon him and calling him into their services as a healer. He has visions and dreams and the ancestors will instruct him through his dreams’. She maintained that she had arrived at this understanding of his condition owing to his particular dreams of bushmen, drums and tribal dancing, which she interpreted as the ancestors calling on him to go into training. Furthermore, she believed his dreams of birds and his experience of an ‘imaginary’ dog licking him was a communication from the forest ancestors. She also maintained that he was hearing the voices of the river ancestors who were giving him advice, instructions and making requests.

She commented that it was not unusual that he should be chosen to be a healer as both his parents are traditional healers. She maintained that at his birth she was given a sign that he was to be special as he was born with a caul (isingxobo). This was reinforced for her in infancy when he cried a considerable amount. She believed that he did not have any control over his illness and was in an agitated state as he had not been assisted in responding to the ancestors’ call.

She reported that she had personally experienced great resistance to accepting the diagnosis of thwasa as the treatment and training is costly and she has lacked the resources to finance it. She specified the cost involved as the high fees of the traditional healer, the expense of clan members travelling to the site of the ritual, and the cost of food, beverages and animals to be slaughtered. However, she commented that once she had accepted his

5. The reference here is to river ancestors who are regarded as white spirits with long blond hair who live under the water. Together with the forest ancestors, they are reputed to be chiefly responsible for the person’s state of thwasa (Bührmann, 1984).
diagnosis it had become imperative to act promptly to avoid irreparable damage to John's mental state.

She outlined the necessary procedure as: (a) incorporation into the household of another traditional healer; (b) medication for sedation, purification and for 'opening the mind' to dreams and messages from the ancestors; (c) dream interpretation; (d) ritual dancing sessions; and (e) ritual ceremonies with animal sacrifices.

She indicated that it was difficult to predict the course of illness; however, she claimed that although the Western medication had helped to alleviate his symptoms, he would not be cured until he had fulfilled the rituals and had taken the herbal medicines. She said that since thwasa calls on the person to live closely with the ancestors, it carries with it the danger of incurring the wrath of the ancestors if proper relations with them are not maintained. She believed that if they continued to resist the call of the ancestors his condition would deteriorate to the point of phambana, insanity (cf Schweitzer, 1977).

Needs of the family
Mother commented that her biggest problem was her dire financial situation. She said that John spends all the money he receives from his grant without contributing to the household expenditures and then demands to be fed.

She could not initiate any proposals for family-based services, but when the options were suggested, she expressed her enthusiasm for participating in all four services. Her order of preference was (a) individual support, (b) education about the illness, (c) contact with other families, and (d) family therapy.
DISCUSSION

Limitations

A number of factors which place inherent limitations on the validity or generalizability of the results have to be considered:

1. Owing to the constraints of time and budget the method of sample selection could not adhere to procedures of random sampling. It is hoped, though, that this study can be used as an exploratory inquiry, and that future research of a more extensive nature will employ a more rigorous method of sample selection.

2. Restrictions of time and budget further affected the sample size which was limited to the relatives of 30 patients in total. Although this factor may affect the generalizability of the results, the quantitative analysis of the groups appears to be less important than the rich qualitative aspects of the narrative presented by each relative. Furthermore, it is believed that with a commitment to the contextual basis of illness meanings, an exclusive focus on generalizations would be inappropriate (Spiro & Swartz, 1990).

3. As mentioned earlier it is possible that the relatives interviewed, who were visiting their family members, represent a more concerned group than the general population of relatives. If this inference holds true, their increased concern may be creating a greater need for and willingness to participate in intervention programmes. However, should there be less interest from other relatives, it is believed that the implementation of family-based services would be more than worthwhile for this sector of the population.

4. In addition, the fact that these relatives are able to travel to VH to visit their family member suggests that it may be more convenient for them to attend
programmes than those relatives who are unable to visit their family members for reasons of time, transport, location of their homes, employment, the task of childminding or any other constraints. An attempt was made to minimize these difficulties by introducing the opportunity for relatives to mention convenient times and alternative venues for the implementation of services.

5. Not all relatives interviewed lived in the same home as the patient prior to his admission. This presents the possibility that these relatives may not be in direct contact with the patient and thus may require less assistance than those family members who were dealing with the patient on a daily basis. Therefore, the responses received from these relatives may have reduced the total number of requests for assistance. In this way results may represent an underestimation of the needs of family members who are in constant contact with the patient.

6. Furthermore, it is possible that the relatives who were living separately may not have directly witnessed the onset of the illness. This brings into question the validity of their phenomenological accounts of the illness, which may be based on indirect reports. However, the likelihood that the reports were assembled on accounts obtained from other family members living with the patient suggests that interpretations in all probability represent an integration of the respondents' and other relatives' belief systems.

7. Since one would expect to yield varying explanations from different family members when more than one relative was interviewed, the uniformity and complementary nature of responses in these cases suggest that relatives may have felt constrained to present a uniform picture and not to show differences in interpretation. This holds implications for future research as it can be recommended that family members be interviewed separately in order to avoid this perceived restriction.
8. It is important to take into account that an interpreter was employed to establish communication with Xhosa-speaking relatives. In order to minimize the hindrance, as mentioned earlier, interviewer and interpreter met prior to the data collection to discuss the interpretation of questions and the use of standard translations for phrases. Furthermore, a back translation was undertaken to ensure reliability.

**Relatives' illness models**

Illness models provided by relatives yielded richly varying understandings of the patient's condition.

In a general sense, it seems that relatives provided a phenomenological account of the illness either in terms of the patient's disruptiveness or in terms of his withdrawal and poor communication. It would seem that the call for advice and educational input would, therefore, be beneficial if it were constructed around these phenomenological accounts. For example, giving advice on how to deal with a violent and aggressive family member, or providing input on the amotivational style that seems typical of many patients, would be relevant in terms of the families' experiences. Although it is recommended that health care workers should extract the particular experience of the relatives concerned, it is believed that the phenomenological accounts of the relatives interviewed in this study can be useful to them. Their value lies in orienting the professional sector to the possible realm of meaning that the illness may hold for the families.

Labels and aetiological explanations provided by relatives suggest that in the majority of cases the condition was understood to be either mental illness, with an implied defect in the person or, alternatively, bewitchment in the form of amafufunyana or spirit possession in the form of thwasa. It is interesting to note that relatives were frequently resistant to believe that the patient had amafufunyana when this was diagnosed by folk healers. It can be hypothesised that their reluctance to accept this diagnosis may be related to the negative
connotation attached to the aetiology, presentation or prognosis of the condition. This seems analogous to the situation where relatives who use the biomedical model are reluctant to accept a diagnosis, such as schizophrenia, for example, provided by the doctor, owing to its aetiological and prognostic implications.

The patients' diagnoses, provided by the doctors, show a noteworthy similarity to the patterns of diagnostic classifications presented in other South African studies (Freed & Bishop, 1980; Gijana & Louw, 1981; Luiz, 1981; Oberholzer, 1985).

A comparative analysis of the ascribed diagnoses and the explanatory models of the relatives could be most valuable in providing information on the relationship between professional and lay models. Although such an inquiry went beyond the scope of the present study, it is believed to be a matter that requires exploration in future research.

The discord between the relatives' responses and these diagnoses on a general level is evident particularly in relatives' scant reference to cannabis abuse, as opposed to its frequent usage as an aetiological factor in the professional sector. It can therefore be predicted that motivation to encourage their family members to refrain from smoking cannabis will be low, unless educational input can clearly portray cannabis abuse as a aetiological factor for relatives to incorporate into their explanatory models. The same holds true for compliance with psychotropic medication, where it is suggested that relatives will not encourage compliance, particularly in a prophylactic role, unless their illness model incorporates a belief in the efficacy of Western medication. The issue of negotiation of explanatory models, which has been addressed in the introductory section and which will be discussed later, is central to this proposed objective.

The fact that a number of relatives could not offer labels, aetiological explanations or their predicted prognosis of the condition may be related to their prior experience in the medical care system where their subjective accounts of the illness may have been considered of little significance to the medical team. It seems that when treatment is focussed on the
disease, the illness experience of the family may be side-stepped in a tacit agreement of its irrelevance to the provision of care.

Their possible reluctance to share their understanding of the illness may be further reinforced by Western biomedical ideology which tends to legitimate its construction of reality as the only clinical reality. The power of the professional sector to promote a normative perspective on health care may be seen to trivialize the expectations and beliefs of the families. This perceived intimidation may create a sense of embarrassment at revealing beliefs in the fear that they will be judged ‘incorrect’ from the professional viewpoint.

A further reason for this finding could lie in the social interaction that surrounded the gathering of the data itself. The interviewer was a white woman working in a setting dominated by white doctors. De Beer (1984) has addressed the issue of discrimination in the South African health system, and has argued that services prejudice black people by subtly reinforcing images of their incompetence. Within the system, patterns of social relations outside of the clinical encounter are reproduced; the image of an African person who cannot provide an explanation for the cause of the family member’s condition mirrors an inferior social role elsewhere.

Furthermore, it can be hypothesized that their inability to provide labels or explanations received from hospital staff may also stem from a lack of dialogue between health care professionals and the family. It is possible that if this dialogue does take place, it may be offered at a time or in a setting when people are too anxious to process the information. Alternatively, explanations may be provided in the scientific discourse of the medical model, with perhaps little attempt at negotiation of viewpoints. Whether the interaction fails to take place, or whether explanations are provided and not heard, remains unclear and is a matter for further empirical study.
For these reasons, it is believed that the neutrality of the interviewer who does not indicate an allegiance to the medical profession is of paramount importance. Furthermore, had it been practically feasible, it might have been worthwhile to follow Kleinman's (1980) suggestion to conduct the interviews during home visits, outside of the professional setting. In this way, respondents may feel less constricted from expressing their viewpoints.

The large percentage of relatives who were responsible for the patients' admission to hospital suggests that ultimately it is the family who function as the most immediate determinative of care. It appears that they activate the health system by deciding when and whom to consult. Following this observation, it would seem that effective communication, which fosters collaboration between families and the professional sector, has ramifications in that it may increase utilisation of services.

**Needs of the family**

The problems experienced by the families in coping with the patient and their expressed fears were generally focussed on the patient's unruly behaviour and his need for constant care. The strain experienced by these relatives who are caring for the patient is usually exacerbated by their concern about the patient's state of ill-health. Their need for support in this situation is apparent, and the commonality of the responses leads to the postulation that their reported anxiety may be alleviated by contact and sharing of these experiences with other families. In addition, individual support and educative input on how to deal with the patient's problematic behaviour could possibly be of benefit to the relatives, since these interventions have proved effective in past research with families experiencing similarly reported strain (Falloon et al, 1982, 1985; Doane et al, 1986, Hogarty et al, 1986; Smith & Birchwood, 1987; Tarrier et al, 1988).

Since the demographic details of this group suggests that most families can be classified as working class, the difficulty that relatives experienced in spontaneously providing requests for services stems perhaps from a working class expectation that personal problems must
be endured. It can be hypothesized that they may have little conception of alternatives since they are possibly rarely faced with options in their daily life and may seldom be in a position of power to voice their opinions. The unfamiliarity of the task was particularly evident in the few responses that claimed 'the doctors know best'. It is also worth noting that the most common response to this open-ended question was a request for financial assistance. This appeal seems to endorse the notion advanced by Maslow's hierarchy of needs (1954), since it suggests that the relatives are more concerned with fulfilling the basic physical needs of the family than alleviating the psychological consequences of their burden. However, the relatives' enthusiasm when presented with options suggested that their poor response to the open-ended question did not arise from a lack of interest in psychological services. This points to the necessity of providing people, particularly those who are not aware of their options, with possible alternatives when undertaking research of this nature.

A major finding in the present study is that although relatives may hold explanatory models that include labels and aetiological explanations which are at variance with the biomedical model of illness, and make use of forms of treatment from folk sectors, they nevertheless overwhelmingly supported the notion of the establishment of family-based services within the existing health care system. This is clearly in evidence in the case study presented. Their willingness to engage with the professional sector and use its provisions as a source of care not only has implications for service, but also endorses theoretical notions advocating the fluidity of explanatory models (Swartz, 1985, 1986). Furthermore, this result demonstrates that people can simultaneously hold contradictory sets of meaning. The postulation of a multiplicity of cultural belief systems is further supported by the finding that most families have used a combination of treatment methods over the course of the illness. The implications that these results hold for cross-cultural theory will be discussed further in the concluding section of the discussion.
The less frequent request for family therapy seems to arise when the relative is aware of a focussed problem in the family arena. This may be the result of the way the question was phrased, with the emphasis on assistance for problematic issues within the family. It can be hypothesized that the comparatively poor response was a result of this narrow definition employed to clarify the meaning of family therapy. Furthermore, it can be postulated that the relatives' lack of experience of family therapy compared to their familiarity with the other alternatives may be contributing to this result. Alternatively, the poor response may be related to the explanatory models of the relatives. With the exception of one aetiological explanation of parental strife, none of the models implicated family dynamics as initiating or maintaining the condition.

It appears that the request for individual support, which was elicited from all respondents, was in part met through the process of the interview. The fact that relatives responded overwhelmingly with an eagerness to share their subjective experience on a verbal and emotional level, and expressed gratitude on conclusion of the interview, lends support to the view that talking about the experience of illness has important therapeutic value (Kleinman, 1988). It seems that when attention to the relative's story is provided empathically and with non-judgmental interest it fulfills the important need of the relatives to be understood and to share their burden with others. The interpretation of illness narratives, as Kleinman (1988) has suggested, is central to the work of healing.

**Conclusion: Implications of this research**

Interviews with relatives of psychiatric patients have elicited a favourable response to family-based services and have provided some strategies for clinical care. The subjective experiences of distress described by relatives together with their positive responses to the options of education, contact with other families, individual counselling, and on a lesser scale, family therapy, provides support for the implementation of these programmes. Their requests for services within existing treatment facilities suggests diminishes arguments which have attempted to mandate separate treatment facilities on the basis of a cultural
essence model. The fact that relatives may hold explanatory models that do not coincide with the biomedical model does not seem to inhibit their support for family intervention programmes within the health care system, even be it input of an educative nature. Thus, what is highlighted is not their different explanatory models, but the commonality of their needs.

Furthermore, this research holds implications for the clinical encounter within the services provided. On this level it supports Kleinman's calls (1980, 1988) for a response to the relatives' suffering based on their subjective experience. It proposes that health care workers should elicit illness meanings in order to offer support and/or interventions which arise directly from the relatives' particular experience of distress. It is suggested that a knowledge of the phenomenological experience and the relatives' understanding of the illness shifts the focus from the disease to the illness, thereby addressing the limitations and distortions of the biomedical approach dominating the health care system. The narratives of the illness experiences presented by relatives in this study can be used to orient the clinician to the illness models held by this particular population. However, it does not substitute for the need to obtain the subjective experience of the particular family concerned.

The eliciting of the client's perspective not only orients the health care professional to a potentially remediable source of distress but also opens the path for negotiation over salient conflicts in models. It is believed that the act of negotiation can be central in the provision of care, since it introduces the possibility of the integration and transformation of explanatory models. Kleinman (1988) highlights the importance of negotiation in an effort to reach a compromise which may be closer to the client's perspective, or closer to the clinician's position, or may simply fulfill the task of demystifying professional and public discourse. It is hoped that in this way we will begin to remove some of the barriers that exist between the health care workers and families which operate against the provision of effective care.
In addition, the findings of this study make a contribution to the theoretical body of knowledge that informs ideological viewpoints.

The notion of cultural belief systems as complex, shifting realities that have diffuse boundaries (Swartz 1985, 1986) has been supported by the characteristic vagueness and contradictory aspects of the accounts provided. The incoherences and constant shifts within explanatory models, together with the wide range of varied experiences offered by relatives, serves to negate the idea of a reified cultural essence and supports the notion that cultures do not exist as static, predeterminable entities.

This holds implications for the way in which we study belief systems. Since these beliefs cannot be regarded as discrete categories that match a particular cultural grouping, it calls for a focus that extends beyond the search for culturally salient meanings, to a search for the common meanings that may be shared by a heterogeneous population.

In conclusion, this research has addressed the need to place meaning back into clinical practice and theory by recontextualising the particular illness experiences of a group of African relatives. It has begun to answer questions related to service needs for this group of people, and has added to the knowledge base informing theoretical perspectives. It is recommended that the next stage of this research would be to address the illness models of the wider population; to cross over the cultural and gender specifications of this sample in an effort to address common issues that might be equally as salient as cultural concerns in recontextualising psychiatric practice. In this way the unique and shared illness meanings can be incorporated into our system of health care, thereby offering treatment not only for the disease, but also for the illness.
REFERENCES


Appendix A

Interview Schedule

No:
Date of interview:
Language of interview:
Interpreter:

**Demographic characteristics of relative**

Name:
Address:
Relationship to patient:
Age:
Education:
Occupation:
History of psychiatric illness:
Other family history of psychiatric illness:

**Demographic characteristics of patient**

Name:
Age:
Date of birth:
Address:
Sex:
Education:
Marital status:
No. of children:
Occupation:
Length of unemployment before admission:
No. of admissions:
Age at first onset:
Age at first admission:

**Composition of household**

No. of employed people in household:
No. of grants in the household:
Other sources of income:

**Understanding of the illness**

Why has your relative been admitted to the hospital?
What is your relative's condition?
Has anyone given you a name for this condition?
Who gave you this name?
What do you understand by ...?
What do you think is the cause of the condition?
What does the condition do to your relative?
Can your relative help it?
Is there any way in which the condition can be made (a) better or (b) worse?
How severe is it? Will it have a short or long course?

**Illness history**

- When did you first notice a problem/behaviour change?
- What was it that you noticed? What was different?
- How have you attempted to cope with your relative's condition in the past?
- Have you been successful?
- Did anyone give you advice?
- What was the advice?
- Who made the decision to bring your relative to hospital?

**Current needs and problems of the family**

- What problems have you experienced as a family in coping with your relative?
- What do you fear most about your relative's condition?
- If the hospital could offer your family a service, what should be included in this service to help your family cope with your relative?
- Rate and discuss whether your family could benefit by:
  - education about the illness
  - support
  - contact with other families
  - help to improve relationships between family members
- What results would you hope your family to achieve?

**Practical arrangements for appointments**

- Day and time most convenient to attend:
- At VH or elsewhere?