Family therapy for schizophrenia: cultural challenges and implementation barriers in the South African context

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Abstract

Family therapy is an effective, evidence based intervention for schizophrenia. This literature review explores the impact of culture on family therapy as a treatment model for schizophrenia and examines how cultural beliefs impact on access to care. Although there is a good deal of evidence to suggest that certain principles of family therapy such as empathy and psycho-education are universal, there is a paucity of literature about the role of culture in designing family interventions for people living with schizophrenia in a culturally diverse setting such as South Africa. It is well acknowledged that cultural ideologies influence families' belief systems of schizophrenia, expected expressed emotion, and levels of stigma in relation to mental illness. Additionally, in adapting models designed for first-world settings, consideration needs to be given to aspects such as language, educational level and accessibility of mental health care facilities. Family therapists are increasingly recognising the need for the study and implementation of evidence based culture-relevant and culture-responsive therapeutic techniques. These techniques need to be cost-effective and will require training, supervision, staff support, and management input in order to become generally available.

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Introduction

In 2008, the global prevalence of schizophrenia was 1% with relapse prevention remaining a challenge to the long-term treatment of schizophrenia in developed and developing countries. An effective, evidence based intervention for schizophrenia is family therapy. Family therapy is a treatment model comprising either single or multi-family groups of relatives and/or patients. Family interventions that psycho-educate, enhance the capacity to problem solve and use strategies to reduce levels of

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Dr L Asmal Department of Psychiatry, Stellenbosch University PO Box 19090, Tygerberg, 7505, South Africa email: laila@sun.ac.za expressed emotion, stress and family burden are shown to reduce the risk of relapse, improve medication adherence and educate families about schizophrenia.² Results from studies done in Europe, Asia and North America indicate that family interventions employing these strategies are common and have demonstrated efficacy in randomised controlled trials.²

The treatment models are loosely based on the concept of family which varies and can represent a traditional nuclear family (comprising parents and children) or an extended family (comprising additional relatives such as aunts, uncles and cousins). Throughout the review we refer to family in its broadest, cultural sense.

One model aims to ease the burden of schizophrenia on patients and their relatives (members of their immediate family such as parents or siblings or extended family such as cousins or caregivers) by creating an atmosphere for problem solving in a mature climate.² This is achieved by discouraging hostility, overt criticism and excessive emotional involvement of patients by family members.⁴ The term "expressed emotion" (EE) was coined by Leff and Vaughn⁵ as a measure of families' involvement in people with schizophrenia. Accordingly, EE is regarded as an important reproducible indicator of the relevance of social factors to the prognosis of schizophrenia.⁶ An appreciation of the relationship between EE and schizophrenia has been fundamental to the development of family interventions for schizophrenia.

There is, however, a paucity of literature about how the structure and content of these interventions should be adapted for people living with schizophrenia in a culturally diverse setting such as South Africa. It is well acknowledged that cultural ideologies do influence families' belief systems of schizophrenia and access to mental health care. Research has also shown that EE may vary in different cultural groups. The implementation of family therapy in accordance with a patient's culture at a conceptual, practical and philosophical level should be well considered.⁷

This literature review has two aims. We aim to firstly describe how cultural beliefs impact on access to care. Thereafter the review will explore the impact of culture on family therapy as a treatment model for schizophrenia.

The intersection between culture, interpretation of mental illness and concept of family

The concept of family, interpretation of mental illness and expected emotion all vary in relation to different cultural groups.

For example, studies conducted in China that compared rural and urban populations found substantial differences in perceptions of the aetiology of mental illness. Participants in a rural based study were more likely to see mental illness as caused by external malevolent spiritual forces and families and were therefore more likely to seek help from traditional healers, such as shamans. On the other hand, families in an urban based study were more likely to blame the illness on internal factors, such as the failure to love or an inability to adapt to a competitive environment. Stigmatisation was also perceived to be greater in urban areas and individuals with schizophrenia were less likely to be employed or to find a partner. 8.9

Diagnosis in African indigenous healing may be better conceived as being related to theories of causation of illness rather than the classification of symptoms into categories as in the taxonomical model of the Diagnostic and Statistical Manual of Mental Disorders or the International Classification of Diseases. 10 For example, spirit possession is the suggested aetiology of Amafufunyana, and blame for any untoward behaviour is placed outside the patient. 11 One explanatory theory of Amafufunyana is that it occurs most often in people who are in a vulnerable or powerless position¹⁰ and functions as a socially sanctioned model in which experiences of inner conflict can be contained. The term ukuthwasa, on the other hand, is used to describe the state of emotional turmoil a person goes through on the path to becoming an indigenous healer. 10 Since cases of ukuthwasa are not considered to be under an individual's control, the person who suffers from it is

deserving of support, sympathy and special treatment. Furthermore, individuals with ukuthwasa are seen as potentially curable. However, some people who experience ukuthwasa do not have a favourable outcome because they are unable to undergo or complete the training to become an indigenous healer. In those cases, a retrospective rediagnosis of ukuphambana (madness) may be given. 10

Themes such as ancestral calling, jealousy, bewitchment, 'evil eye' and guilt are common explanatory models for schizophrenia in Africa. African patients with schizophrenia treated with antipsychotics and admitted to psychiatric hospitals are likely to believe that the treatment is only symptomatic, such as for behavioural control. ¹² These patients may then seek further intervention from indigenous healers in an attempt to address what they believe is the actual cause of the illness. Families of patients with schizophrenia may also share these beliefs and assist their relatives in seeking help from indigenous healers.

Individualism and individual autonomy are prominent features of the Western medical framework and the person is viewed as a self-contained entity. In contrast, traditional African cultures are described as collective and emphasise the position and responsibility of the individual within the group. Family and kinship patterns assign different roles, status and power among group members. ¹³ This may influence decision-making regarding treatment interventions and interactions between family members may differ from traditional western models. An awareness of the contrasting concepts of 'person' between Western and African cultures is important for the successful implementation of a family intervention.

Stigma, schizophrenia and culture

Culture could determine levels of stigma in relation to mental illness, a relationship that has been explored in a number of South African studies. One such study looked at the attitudes and beliefs of relatives of Xhosa patients with schizophrenia and found that 67% of family members believed that witchcraft or spirit possession was related to the onset of schizophrenia. However this belief did not necessarily safeguard the patient against stigma. A significant number of the relatives believed people with schizophrenia to be dirty (52%) and dangerous (44%). 12

A more favourable outcome has been described in patients in developing countries. It has been argued that traditional family support structures and higher levels of family tolerance towards people with schizophrenia contribute to a better course and outcome in low- and middle-income countries. 14 This was originally reported more than 20 years ago in a World Health Organisation collaborative longitudinal study in 10 countries. 15,16,17,18 More recently, analyzing the results from another World Health Organization collaborative project, the subject was re-examined. Once again, evidence of differences in the course and outcome of the illness in favor of the developing country centers was found. Potential sources of bias were examined, and none were able to explain the findings. 19

However, the notion that schizophrenia has a better outcome in developing countries has itself been challenged, as have the presumptions of the nature of family support for people with schizophrenia in developing

countries.²⁰ Studies have consistently found that long-term outcome in schizophrenia is dependent on adequate treatment. A recent study has again found that patients with schizophrenia not on treatment have a higher mortality rate than patients treated with any antipsychotic medication.²¹ It is thus unlikely that patients with schizophrenia in the developing world would have a better outcome when they have many barriers to accessing treatment.²² Access to treatment varies within and between developing countries and is influenced by a number of factors including migration, urbanisation, economic insecurity, social inequalities and changes in family structure and support networks (such as change in caregiver roles after death from HIV/AIDS).²⁰

A retrospective study conducted in Nigeria found that 4% of people with schizophrenia were homeless despite coming from traditionally structured family backgrounds. Studies based in Ethiopia, Nigeria and rural China have shown homelessness or housing instability in people with schizophrenia to be greater than in many developed countries. ²⁰ In developing countries where public mental health resources are limited, families caring for people with schizophrenia may struggle with the strain of coping with a chronic and severe mental illness. In the absence of support for the families themselves, these traditionally supportive family networks may break down with time. This may place the patient at risk of victimisation, homelessness and a poorer outcome. ²⁰

Culture mediating the relationship between family therapy and schizophrenia

Culture has been shown to influence EE and studies have explored the role of cultural ideas and practices in relapse. In western based studies, a relapse rate of over 50% is experienced when patients return to high-EE families compared to a 20% relapse rate when patients return to a low-EE family setting.²³

There have been a number of studies among Mexican Americans. 24,25 Kopelowicz et al25 compared the tolerance threshold of hostility and criticism by others of Mexican Americans and Egyptians with schizophrenia with that of British and US Anglo Americans. They found that Egyptians and Mexican Americans with schizophrenia tolerated higher levels of critical comments and hostility than British or US Anglo Americans.²⁵ Similarly, African American people who experienced caregiver criticism, a key component of high EE, did not necessarily relapse. 25,26 African American caregivers' intrusive behaviour during conflict may be interpreted as a sign of sincerity and genuine concern and the interactional process is less likely to predict relapse symptoms.²⁶ There is a conceivable risk of increasing stress should a clinician unknowingly focus on reducing critical and intrusive behaviours in families where these types of interactions are positively adaptive.27

Nonverbal behaviours may also be interpreted differently by clients of different cultural backgrounds. The meaning of maintaining eye contact, the concept of personal space and how families arrange the seating during a session can vary between cultures and the unknowing clinician may misidentify salient issues by not fully understanding the cultural context of the nonverbal behaviour.²⁸

Theoretically, the attribution of psychotic symptoms to spiritual forces may lead to relatives being more accepting of untoward behaviour since it is believed that the patient is not fully in control of their actions²⁹ thereby creating a natural 'low-EE' environment. Although the belief that symptom manifestation is largely outside the patient's control may be beneficial in some respects, this model of illness focuses on just one cultural aspect in the complex family dynamic in schizophrenia.

Studies examining the relationship between EE and relapse found that Mexican American samples have a lower proportion of high EE families than British and US Anglo American samples (although EE was still associated with relapse in all groups). ^{24,25} Similarly, in a multicentre family intervention study for first-episode schizophrenia based in Chandigarh, Aarhus and London, Leff et al. ³⁰ found a significant association between EE and relapse in all centres. However, compared with the North Indian sample, the European centres had a much higher proportion of relatives with high EE (54% compared to 23%). The study investigators postulate that the better outcome at one-year follow-up in the North Indian sample may be due to the high proportion of relatives with low EE.

Alvidrez³¹ concluded that African Americans were more likely to attribute the symptoms of schizophrenia to religious or spiritual factors, which made caregivers more accepting of odd behaviour and thoughts and less controlling of psychotic behaviour. Likewise, in a study by Breitborde et al³², high EE caregivers were more likely to believe that the ill relatives' actions were as a result of human agency (and thereby more likely to be intentional and within the ill relatives' control) than low EE caregivers. The authors postulate that the caregiver infers what meaning or goal the ill relative attempts to convey during periods of illness and this process of understanding is fundamentally a cultural one. This heuristic framework may be a useful way to explore the influence of indigenous healing on schizophrenia in South Africa.

In a convenience sample of 187 African, European and Latino American women at a general medical clinic, Alvidrez³¹ found that women who believed that psychiatric symptoms had a religious or supernatural basis were less likely to attend mental health centres for treatment. In the same study, it was found that if friends or family had previously attended mental health centres, women with current psychiatric symptoms were 2.5 times more likely to seek treatment for themselves. Certain cultural groups, such as Latino Americans, may to be more likely to believe that the family shares responsibility for an individuals problems³³ and that mental illness is best treated with the family.34 Studies have found that family members who believe that their relatives with schizophrenia are in control of their symptoms are more likely to drop out of family therapy.35

A study based in Chennai, India, found that women with schizophrenia were stigmatised by the illness itself and by the social judgment of divorce and separation.³⁶ Additional evidence from Chennai suggests that even when mental health facilities are accessible and free of charge, living in an extended family is a risk factor for not being brought in for treatment.³⁷

Implementation barriers

Any psychosocial intervention requires finances, time, adequate facilities, and trained, motivated implementers all of which may be affected by larger attitudinal, knowledge and systemic implementation obstacles. 1 The heavy workload of busy mental health professionals in a limited resource setting needs to be considered as well as the impracticality of large-scale implementation of family interventions by psychiatrists or psychologists given the shortage of both groups of professionals in South Africa.38 Studies have shown that knowledge about evidence based advantages of family psychoeducation (such as reducing hospitalisation or relapse rates) do not convince most clinicians to change their working habits and adopt new clinical practices for schizophrenia.39 In the planning of any intervention for family therapy, local operational barriers need to be considered.1

For family members, a number of practical concerns such as transportation, work commitments and competing demands on energy and time may influence adherence (Kritzinger J, Swartz L, Mall S, Asmal L. Family therapy for schizophrenia in the South African Context: Challenges and pathways to implementation. 2010; Unpublished literature review).

Relatives of people with schizophrenia may also feel stigmatised by the illness and consequently may feel uncomfortable revealing details about psychiatric illness in their families or with being identified as regular attenders at psychiatric facilities.¹

Conclusions

Family interventional programmes are widely used internationally and are effective adjuncts to pharmacotherapy in patients with schizophrenia. It is, however, crucial when implementing such programmes to consider cultural factors that may influence the expression and experience of schizophrenia in fundamental ways.

There is a good deal of evidence to suggest that certain principles of family therapy such as empathy and psychoeducation are universal and are suitable for implementation in South Africa. Integration of these basic principles into locally based family intervention programmes is suggested regardless of the patient's and family's cultural background.

To ensure successful family based therapy models in South Africa, health care workers would require training in local cultural differences and in the customs of traditional healing systems. Training will also need to raise awareness in clinicians of their own perspectives and biases. Additionally, in adapting models designed for first-world settings, consideration needs to be given to aspects such as language, educational level and accessibility of facilities.

Although family interventions for schizophrenia have been studied in a range of international settings there is almost no systematic research on this topic on the African continent. Family therapists are increasingly recognising the need for the study and implementation of evidence based culture-relevant and culture-responsive therapeutic techniques. Further research is needed to examine whether modifications in content and outcome of international family therapy models is required for the South African context. The role of culture in influencing the

concept of the family in relation to schizophrenia should be examined as an additional area of research.

Globally, the gap between showing efficacy and the routine implementation of effective services appears particularly hard to bridge. A proposed family intervention programme adapted for the local context needs to be cost-effective and will require training, supervision, staff support, and management input in order to become generally available. To ensure buy-in from policy makers and funders, potential barriers to service provision and the design of a cost-effective family intervention programme needs further research. From a clinical perspective, understanding the patient's and family's explanatory model fosters trust and is essential to a collaborative treatment plan.

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