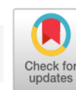
Journal of Medical Research and Health Sciences
Received 10 Dec 2021 | Revised 25 Dec 2021 | Accepted 24 Jan 2022 | Published Online 13 Feb 2022

DOI: https://doi.org/10.52845/JMRHS/2022-5-2-3
JMRHS 5 (2), 1779–1785 (2022)
ISSN (O) 2589-9031 | (P) 2589-9023

RESEARCH ARTICLE

Open Acess Journal



Explore and Develop a Culturally Adopted Behavioral Psycho Educational Family Intervention for Caregivers of Schizophrenic Patients in Egyptian Context.

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Abstract

Background: Schizophrenia is a severe enduring psychotic illness that has a profound impact on the life of the sufferer and imposes a heavy burden on their families and the community. Family interventions (FIs) are the accepted model for addressing caregivers' needs for support and information. However, there are considerable variations in their content and application. The National Institute for Clinical Excellence (NICE) has recommended that FIs should be adapted when they are delivered to non-Western populations. To date, there are few published studies, which examine FIs in the Egyptian context.

Aim: To explore and develop a culturally adopted behavioral psycho educational family intervention for caregivers of schizophrenic patients in Egyptian context.

Results: Four components were identified as the most frequently used out of the systematic review. Deep structure was adopted for cultural adaption. SWOT analysis identified areas of uncertainty regarding acceptability of the components. Focus group members recommended modifications to the components of the intervention to ensure its accept-ability and feasibility in the local setting. Data synthesis was conducted and the intervention was designed.

Methodology: Development phase involved four stages**: 1).** Iden-tifying the strategies used for the cultural adaptation of FIs in non-Western cultures **2).** Identifying the key components of FIs tested in the studies included in the Cochrane systematic review **3).** A SWOT analysis to identify the strengths, weakness, opportunities and threats for the potential components **(4).**A focus group study involving caregivers and health professionals to explore the acceptability and feasibility of delivering FI in the Egyptian context. Data synthesis determined the design of the proposed intervention according to the findings obtained from the previous stages.

Results: Four components were identified as the most frequently used out of the systematic review. Deep structure was adopted for cultural adaption. SWOT analysis identified areas of uncertainty regarding acceptability of the components. Focus group members recommended modifications to the components of the intervention to ensure its acceptability and feasibility in the local setting. Data synthesis was conducted and the intervention was designed.

Conclusion : This study provides evidence of the potential efficiency and acceptability of a culturally sensitive FI for caregivers of people with schizophrenia in Egypt. However, more work needs to be done to overcome the practical challenges and test the feasibility of the intervention in more rigorous way. Also, the efficacy of the intervention needs more rigorous investigation in the context of a small scale RCT.

Keywords: Behavioral psycho education, Family intervention, Care-givers, Schizophrenic, Egyptian

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1 | INTRODUCTION

Schizophrenia is a major mental disorder which causes complex disturbances in thinking, perception, emotions and social behaviours. [1] Historically, the focus of treatment for people with schizophrenia was mainly hospital- based. A shift from hospital-based care for people with schizophrenia towards care in the community was initiated in the West in the late 1960s, and has subsequently spread internationally. [2] The majority of people with schizophrenia live in close proximity to their families, which can be stressful for the individual sufferers and the family members who care for them. [3] A stressful environment can contribute to recurring episodes of illness and exacerbation of acute symptoms in vulnerable individuals. [4] Caring for a family member with schizophrenia can place a severe burden on the whole family and can impose significant personal, financial, social and emotional demands. [3], [5]

Over the past three decades, family-based interventions program have been developed for people with schizophrenia. [6] These program can help individuals to integrate in the community by providing information and support that can enable them to cope more effectively. They also offer protective strategies against relapse and recurrent episodes of illness. [7], [8]

The impact of these program upon the clinical and social outcomes of people with schizophrenia has been demonstrated in a number of systematic reviews and meta-analyses. [9], [10] They have shown a reduction in relapse rates and have demonstrated other benefits, including improvement of family well-being and reduction of family burden. [11] They have been widely used across the Western world and are strongly recommended in treatment guidelines for schizophrenia. [12]

Family Intervention (FI) program vary with respect to their content, application and theoretical orientation. This makes it difficult to establish which specific treatment, model, or combination of techniques is the most effective. [13] Recent literature has emphasized the need to determine the critical components of the intervention prior to implementation. [14]

Until now FI program have been derived from Western approaches that reflect their origins in the United States and Western Europe. The National Institute of Clinical Excellence (NICE) has recommended that family interventions need to be adapted in order to cater for the needs of non-Western populations. [15] A limited number of studies have looked at the efficacy of family interventions in non-Western cultures such as Chinese, Latino, Indian and Arab populations. [16], [17], [18]

However, there have been less published studies which have assessed the efficacy of family interventions in Arab countries, such as Egypt. Egyptian culture, including religion, family structure, and traditional health beliefs influence people's perception and management of mental illness. Mental health services are poorly developed, and family therapy is not well established in Egypt. Lack of community care and support from health professionals leave the families ill- equipped to care for their ill relatives. It is unknown whether the existing Western models can be applied successfully in Arab culture. [19] [20]

2 | MATERIALS AND METHODS

Study design and purpose

Qualitative research involving focus groups and qualitative interviews was used in the development of the intervention. The justification for using qualitative research in the exploratory phase of the study emerged for a number of reasons; Firstly, previous research about family interventions relied heavily on quantitative research, mainly RCTs. Whilst these studies yielded valuable data, there was an absence of

Supplementary information The online version of this article (https://doi.org/10.52845/JMRHS/2022-5-2-3) contains supplementary material, which is available to authorized users.

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research. which investigated the perspectives „input"of those receiving the intervention (i.e. caregivers) or those delivering it (i.e. health professionals). Sec-ondly, the details of the "real world" and unique experiences of families regarding their concerns, and specific cultural and spiritual needs, would be difficult to collect with a "deductive" approach of research enquiry. [21]

Building on the findings from the literature re-view conducted earlier (Literature Review), gaps in knowledge were identified regarding the strategies used to adapt family interventions in non-Western cultures and the key components and elements of family intervention program. The aim of develop-ment phase is to adapt and design a culturally ac-ceptable and feasible family intervention program through addressing these gaps. The development phase is then divided into 4 stages:

The Medical Research Council (MRC) framework for the development and evaluation of complex in-terventions was used to guide the structure of this study. [19], [21]

Table 1: tages of developing interventions

Step 1	Development of the intervention	
Stage 1	A culture review	To identify the adaptation strategies that have been made when using FI program in non-Western cultures.
Stage 2	An update of Cochrane FI systematic review	To identify key components of family intervention program.
Stage 3	A SWOT analysis	To assess strengths weaknesses, opportunities and threats of each of the potential components and shape the questions for the focus groups.
Stage 4	A focus group study	To explore the acceptability and feasibility of the potential components that could be used in the Egyptian context.
Step 2	**Design of the Intervention**	
	To synthesize the findings of stage 1, 2, 3 and 4 and design the intervention.	

Purpose : To explore and develop a culturally adopted behavioral psycho educational family inter-vention for caregivers of schizophrenic patients in Egyptian context.

Stage One: Cultural review of Family Interven-tions (FIs)

3 | RESULT

Twenty-five studies were identified by the search; ten studies were excluded as they failed to meet the inclusion criteria (studies that only included the patients without the families, review studies, or studies which examined family interventions for other mental health disorders). Fifteen studies met the inclusion criteria. Fourteen of the included stud-ies were randomized controlled trials and only one was non-randomized control trial. The majority of the studies were conducted in Eastern cultures, (ten in China, one in Malaysia, one in Korea, one in India, one for Vietnamese speaking families) and only one in Africa (Malawy). There was no study that has been conducted in Arabic- speaking coun-tries. The outcome measures varied according to the aim of the studies. Outcome measures included patient- and caregiver-related parameters such as; measures of knowledge, burden of care, attitude to mental illness, subjective distress, stigma, coping, and self-efficiency. Other outcomes included psy-chiatric symptoms, medication adherence, relapse, re-hospitalization, employment duration, and use of services.

Key summary points

- Strategies for adaptation could be either surface or deep; most of the reviewed studies used surface adaptation strategies.
- There are no consistent results regarding the ef-fectiveness of family interventions in non-Western cultures.
- Stakeholders" perspectives and views about the intervention are highly recommended in the planning of family intervention program in non-Western cul-tures.
- Psychoeducation component is the most common and feasible to be conducted in developing countries with limited resources.

Stage Two: Identifying the key components of FIs

Results

The Cochrane review covering the period from 2000 to 2018 has identified 43 studies that met its inclusion criteria using randomized and quasi-randomized tri-als. The reasons for exclusion ranged from studies

with inappropriate control groups, studies with less than five sessions of interventions, or patients who had illnesses other than schizophrenia or schizoaffective disorder. Searching until June 2018, an additional 5 studies were found and added. Thus 48 studies were examined for the key components and key elements involved.

In summary, identifying the key components of family interventions is problematic due to the diverse nature of research studies in this field; this review identified the most common components that have been used in the studies according to their frequency of use. Psychoeducation, problem solving, and communication skills were identified as the most

frequently used components in the trials. Key elements of the intervention (duration, patient involvement setting and number of sessions) varied in the trials, and thus the findings are inconclusive. In terms of duration, the intervention is recommended to last for nine months.

Key summary points

- Psychoeducation is an essential, common, and frequently used component in the reviewed studies; however, it is not as effective as when it is used in combination with other behaviour-oriented approaches.
- Falloon"s 1985 model was the most replicated model, with the most positive results.
- Longer interventions (three to nine months) appeared to be more effective, particularly in reducing the risk of relapse.
- Group approach was reported as more cost-effective.
- Patients" involvement in the intervention is preferred and recommended, although not always applied.
- No difference was found in the effectiveness of setting between home- and clinic- based FI.
- Relapse was used as primary outcome in the majority of studies which have offered prolonged duration of treatment.

Stage Three: SWOT Analysis

The aim of the SWOT analysis in this stage was (a) to assess the strengths, weakness, opportunities and threats of each of the potential components and (b) to identify the areas of uncertainty or concerns to be addressed in the focus group discussion in the next stage.

After collecting the required information about each of these components, a brainstorming approach was used to perform component analysis through asking the following questions:

- What are the current strengths of the identified potential component?
- What are the relative weaknesses?
- What opportunities does this component present to build on the current strengths and to address its relative weaknesses?
- What potential threats or obstacles need to be overcomed to take advantage of the opportunities?

To summarize, in the third stage of the development phase, SWOT analysis was used to critically analyze the identified components of family interventions. The components were assessed for strengths, weaknesses, threats and opportunities. Also, it was used to identify topics to be discussed with the stakeholders in the next stage. This section introduced the SWOT analysis; the next section presents the focus group study (fourth stage) conducted to explore the feasibility and acceptability of the proposed intervention in the Egyptian context.

Stage Four: Focus Groups

The aim of this stage was to explore the views of the stakeholders, including health professionals and caregivers of people with schizophrenia, regarding the feasibility, acceptability, and barriers to delivering the family intervention in Egypt.

Specific objectives included:

- To explore health professionals" and caregivers" views regarding the most feasible ways of delivering the intervention, and the acceptability of the potential key components and key elements identified in the previous stage.
- To explore the caregivers" specific concerns, educational needs, and cultural beliefs in relation to caring for a relative with schizophrenia.
- To identify the barriers and motivations of delivering the intervention.

Findings of the focus groups

Seven focus groups were conducted; five groups with health professionals and two groups with the caregivers in the outpatient clinic in El-Mammoura Hospital, Alexandria.. The high proportion of focus groups (n=5) with health professionals compared to those conducted with caregivers (n=2) was due to the difficulties faced in recruiting caregivers. caregivers who attended the outpatient clinics were either coming for a follow up reason, emergency (associated with police) or initial admission. Those who came for the admission purposes were in bad state of mind as they were either travelling from far places, occupied with the patient who is already agitated or in uncontrollable state (shouting, restlessness), or very exhausted for previous unsleeping nights. They often showed preservative attitude due to the stigma of the illness and unfamiliarity with the author.

The focus groups were held separately for each occupational group (two focus groups were conducted with nurses, two were conducted with psychiatrists, one was conducted with social workers, and two were conducted with caregivers). The focus groups were conducted in Arabic, the main and official language of the participants and the discussions lasted between 45 and 60 minutes. The size of the focus groups ranged from three to eight participants according to the shift system of the staff or the number of people who turned up to the session.

Summary of key points

- The aim of this stage is to explore the acceptability and feasibility of the identified key components and key elements of the intervention.
- This section presented the methodology of a qual-itative focus group study involving caregivers and health professionals (nurses, psychiatrists and social workers) in Egypt and the findings of the focus groups.
- Seven focus groups were undertaken comprising 37 participants from a range of healthcare profes-sionals together with the caregivers.
- The focus group data was shaped by two core con-cepts; the acceptability and feasibility of the potential components and key elements.
- The findings of focus groups showed that the families needed to feel accepted and informed about the illness and its management.
- Participants recommended that the content of the intervention would be useful if it involved information and emotional support as well as culturally relevant coping skills.
- Problem solving and communication skills components were viewed as unacceptable.

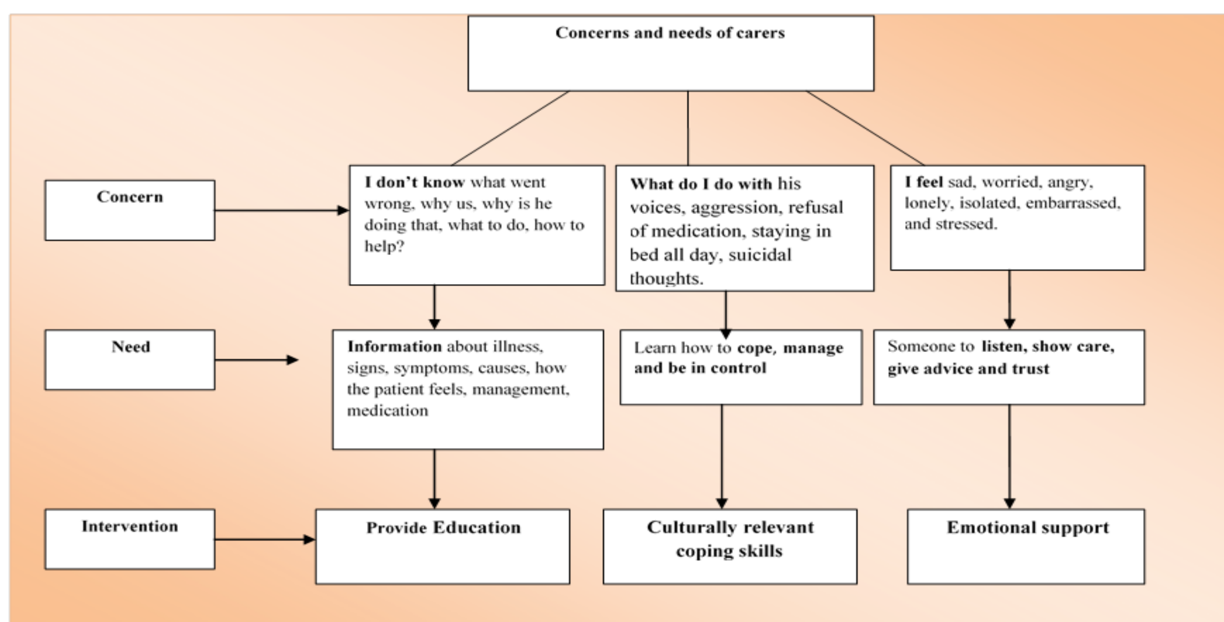

FIGURE 2: Concerns and needs for caregivers

Table 2 Illustrate the developed intervention, each session, its aim, tools and outcome

Week	Session	Aim	Tools	Proposed outcomes
1	Introduction	Establishing a trustable relationship	Informal discussion, social conversations and answering questions about the intervention.	Get the family members familiar with facilitators, group and the therapeutic approach.
2	The family response to mental illness	Normalising the families" experiences, giving chance to express feelings, showing appreciation and understanding to their painful experience.	Discussion	Show support and empathetic understanding to the families" experience Enhance the practitioner-family relationship
3	Schizophrenia	Provide information regarding the nature of schizophrenia, aetiology, symptoms, and course of illness.	Video, discussion	Increase the understanding about the illness
4	Schizophrenia from within	The subjective feelings of the ill person. Sign and symptoms of the illness (hallucinations, delusions, negative symptoms)	Video, discussion and role play	Increase the knowledge regarding the illness and the hidden inner experience of the sufferer.
5	Beliefs around schizophrenia	Discussing the cultural beliefs and perceptions about schizophrenia. The influence of culture, media, religion on the public views of people regarding mental illness.	Discussion	Provide culturally sensitive understanding about the illness and correct some myths around it. Provide correct information about the illness that match with the caregivers' beliefs.
6	Medication	Provide information about medication, side effects, and general instructions.	Discussion	Increase knowledge about medications. Encourage medication adherence.
7	Coping skills (Holistic) approach)	Provide information on how to manage with everyday stress and problems using the Islamic model of mental health (concept of *ruh* (spirit), *qalb* (heart) and *aqel* (intellect).	Discussion	Enhance their spiritual and emotional capacity to cope better with the illness.
8	Management	Provide information about setting limits, simple communication, and reduction of involvement.	Examples from real- life situation and discussion	Increase the families" confidence to provide care effectively. Learn how to handle with daily situations and manage difficult behaviours.
9	Signs of relapse prevention	Provide information on early signs of relapse and how to manage it.	Discussion	Increase knowledge regarding relapse prevention strategies and how to detect early signs.
10	Empowering the families.	Providing emotional support	Discussion	Increase their confidence in managing ill relatives' behaviour and their own stressors independently.

Summary

In summary, this chapter synthesised the results of the four developmental stages. It illustrated how the final decisions regarding the key components and key elements (setting, patient involvement, outcome, duration) were undertaken backed up by the findings of the four stages. The chapter presented the final design of the proposed intervention to be tested for feasibility and acceptability in the next phase of the study.

Ethical consideration

Prior to any contact with participants, approval to conduct the study was first gained from the hospital. The proposal and the discussion guide were translated into Arabic by the researcher and sent to the ethics committee in the Mental Health Research Department in Cairo. In addition, permission to use the tool was obtained. Written consent was obtained from all participants. Participation was voluntary and no identification data was collected.

Ethical compliance: Approval was obtained from ethics committee in the Mental Health Research Department in Cairo.

Conflict of interest: The authors declare that they have no conflicts of interest.

Acknowledgement: The authors would like to thank the participants.

Funding: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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How to cite this article: Wahid R., Lazarus ER. Explore and Develop a Culturally Adopted Behavioral Psycho Educational Family Intervention for Caregivers of Schizophrenic Patients in Egyptian Context.. Journal of Medical Research and Health Sciences. 2022;1779–1785. https://doi .org/10.52845/JMRHS/2022-5-2-3