

Psychosocial Family Interventions for Relatives of People Living with Schizophrenia in the Arab World: Systematic Review

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Abstract

Aim and objectives To synthesise the available evidence about culturally-adapted psychosocial family interventions in the Arab world. The review identifies the content and characteristics of these interventions, determines the strategies used to successfully adapt them to the Arab culture, assesses the feasibility and acceptability of the interventions, and evaluates the effectiveness of these interventions for service users and their families.

Background Family interventions in schizophrenia are evidence based and have been adapted to different cultures to improve their effectiveness and acceptability in different settings. The Arab world has a unique set of sociocultural norms and values that cannot be ignored when developing or implementing such interventions. There is a lack of research on the feasibility of delivering family interventions for schizophrenia in the Arab region. **Design:** systematic review **Method** Five electronic databases were searched including MEDLINE, CINAHL, Cochrane Library, PsycINFO and EMBASE for articles written in Arabic and English from inception to 2019. Data were extracted and synthesised narratively.

Result Five studies were retrieved from the search: two randomized control studies, two non-randomized studies and one qualitative study. There is a paucity of evidence about culturally- adapted family interventions in the Arab region. However, the cultural adaptation process was comprehensive and the implementation was feasible and acceptable. The methodological quality of the included studies was generally poor, so there is a risk of overestimating the effect of the interventions due to lack of rigour and the presence of bias.

Conclusion The present review provides the foundation for future work about family interventions in the Arab world. The content and characteristics of the interventions were identified but the effectiveness cannot be determined because of the poor methodological quality. The adaptation process was comprehensive but rigor in testing adapted interventions is largely absent.

Background

Family interventions have consistently shown positive outcomes for individuals living with schizophrenia and their families (1-3). They have been recognized as evidence-based practice and are recommended by national and international clinical guidelines (4-6). A major criticism of such interventions is that they are based on Western models and therefore they may not be applicable to other countries without cultural adaptation (7). Cultural adaptation is “the systematic modification of evidence-based treatment or intervention protocol to consider language, culture, and context in such a way that is compatible with clients ‘cultural pattern, meanings and values” (8). Cultural adaptation aims to modify interventions to fit the cultural context of each diverse group to enhance acceptability, engagement, satisfaction and, ultimately, their effectiveness (9-11). A considerable amount of literature has suggested that cultural context influences all aspects of diagnostic and treatment process (8, 12). Therefore, people tend to accept and engage in interventions or treatment when they are congruent with their beliefs and values (9).

Recently, researchers have shown an increased interest in culturally adapting family interventions to different cultures to improve the acceptability and effectiveness of the treatment (7, 13-18). These studies have shown that there is optimal benefit when interventions are tailored for a specific culture. A recent meta-analysis of culturally-adapted mental health interventions found a moderate to large effect for such adaptations (9). Another systematic review by Degnan, et al. (2016) analyses the nature and outcomes of culturally-adapted psychosocial interventions in schizophrenia. This comprehensive review, which includes forty-six RCTs and 7,828 participants, showed significant post-treatment effects in favor of adapted interventions. The review suggested a framework for cultural adaptation, including nine themes, concluding that the efficacy of the adapted intervention is proportional to the degree of cultural adaptation. In this review, the majority of studies were adapted for a majority population, which is unique compared to the other reviews, which were mainly for minority populations (9, 13, 19). Furthermore, the heuristic model proposed by Degnan et al. (2016) provides clear guidance for cultural adaptation in comparison to previously conducted reviews. However, they included varieties of cultures and psychosocial interventions for schizophrenia. Furthermore, the available adaptation frameworks have mostly been developed in Western countries for minorities groups, but might not work for indigenous populations (9). Therefore, this review will focus on cultural adaptation of family interventions in the Arab world.

The Arab region consists of 22 countries that share a common language, cultural traditions and history. The Arab region is home to one person in every 20 of the world's population and with the world's current highest rates of population growth (20), the population continues to rise. This region has more than half of the world's oil resources but there is significant inequality and wealth disparity between countries. About half of the countries are considered low and middle income countries (LMICs) (21). Furthermore, during the last 70 years the Region has experienced war and conflict, causing migrants to outflow to Europe and other countries globally (20). The Arab culture including religion and tradition plays an important role in the political, social, and economic life of this Region. Therefore, knowledge of Arabic cultural beliefs and practice are important in order to provide culturally competent care and avoid inappropriate intervention delivery or poor compliance (22).

A scoping review was conducted in the Gulf Cooperation Council (GCC) about the mental illness research in the area (23). The authors found a gap in developing and testing culturally-adapted interventions and therefore recommended such work to help in the development of practice and policy. Many of the Arab countries especially the GCC countries have the resources but there is still a real underdevelopment of such interventions. It is important to conduct a systematic review of local studies in the Arab world because the experience of mental illness are linked to the sociocultural context of the region (23). In addition, there are many practical barriers to care in the Arab world such as low literacy level, different explanatory models of mental illness, stigma, and lack of resources and trained health care providers (24). Consequently, developing an intervention with cultural relevance and within existing health services could increase the acceptability and ensure efficient use of the available resources. In order to develop effective interventions for schizophrenia, we need to understand service-user and carer previous experiences of family interventions in the Arab countries to learn from successes and failures. To date,

little is known about culturally-adapted family intervention for schizophrenia within the Arab culture making it difficult to design and test such an intervention.

The aim of this review is to synthesise the available evidence about culturally-adapted psychosocial family interventions in the Arab world. It will identify the content and characteristics of these interventions, determine the strategies used to successfully adapt them to Arab culture, assess the feasibility and acceptability of the interventions, and evaluate the effectiveness of culturally-adapted interventions for service users and their families.

Methods

Design

A mixed-method systematic review following the Preferred Reporting Items for Systematic Review and Meta-analysis was conducted (25). The protocol is registered on PROSPERO with registration number: CRD42019117180 <https://www.crd.york.ac.uk/prospero/>

Search Strategy

Five electronic databases were searched including MEDLINE, CINAHL, Cochrane Library, PsycINFO and EMBASE for articles written in Arabic and English from inception to August 2019. The databases were searched using the keywords and their associated Medical Subject Heading (MESH) “schizophrenia or psychosis” AND “Arab or Bahrain or Egypt or Iraq or Jordan or Kuwait or Lebanon or Libya or Morocco or Oman or Palestine or Qatar or Saudi Arabia or Sudan or Syria or Tunisia or United Arab Emirates UAE or Yemen”. When the key terms of “family intervention or psychosocial intervention” were added, it limited the number of results to 5-8 studies only. Hand searching for studies in Arabic journals and reference lists of previous related reviews were done to identify any additional relevant studies. An example of the search strategy for a PsycINFO is available in supplementary material.

Inclusion and exclusion criteria

Articles were included if they met the following inclusion criteria: 1) any study design that evaluated culturally-adapted psychosocial family interventions in the Arab world. 2) Participants are relatives or family members who are caring for an individual with schizophrenia or related disorders. 3) The majority of carers (70% or above) are adults of 18 years or older, and the majority (70% or above) of the patients have schizophrenia or related disorders based on ICD-10. Articles were excluded if 1) the intervention did not include family members or caregivers 2) Non- Arabic or non-English language.

Screening

The results were exported to evidence (www.covidence.org), an online software product that improves the efficiency of creating and maintaining Systematic Reviews. Based on predetermined inclusion and exclusion criteria, the team members independently undertook the initial screening of titles and abstracts. Two members of the team (A.S & L.R) independently screened the full texts of selected abstracts.

Data Extraction

The extraction sheet was developed in Excel and refined after piloting it on three articles. Data extraction elements included study details, intervention characteristics, adaptation process, feasibility, and acceptability of the studies. The principle investigator extracted the data from the articles and entered them into the data extraction form, and then another member of the team verified them. The developed extraction sheet is available from the author. Discrepancy during the process of screening or extraction was resolved by team discussions.

Methodological Quality Assessment

Given the methodological variation of included studies, a range of quality appraisal tools were utilised. For RCTs, the Cochrane Collaboration's tool for assessing risk of bias was used (26). It is a robust tool for assessing RCTs across six domains of risk (selection, performance, detection, attrition, reporting and other biases) (Zeng, et al., 2015). For non-randomised studies, we used the tools adapted from JBI for non-randomized trials; for qualitative studies we used the one adapted from JBI (27). These tools have been developed using a transparent process and have been tested in many previous systematic reviews (See additional file 1 for the tools).

Data Synthesis

Meta-analysis was not possible due to the diversity of designs, outcomes measures and tools used. A narrative review was conducted focusing on the objectives of the review to draw conclusions and generate areas for future work about family interventions in the Arab world (Dochy, 2006; Green, Johnson, & Adams, 2006). Quantitative and qualitative studies were analysed and the results were narratively synthesised according to the framework proposed by Popay, et al (28). The review included one qualitative study; therefore, it was reported narratively with the quantitative studies. The synthesis was initially conducted by the first author and discussed regularly with the research team.

Results

Search results

The database search yielded 933 titles and abstracts in addition to another two articles from hand searching. Following the removal of duplicates, 890 titles and abstracts were screened, after which 874 were excluded. The full-text articles of 13 references were obtained and considered against inclusion and exclusion criteria. Eight studies were excluded for different reasons, as shown in PRISMA chart. These left five studies to be included in the final review (see Fig.1 for the PRISMA flowchart).

Insert figure 1 here

Study Characteristics

Five studies were retained as they met the inclusion criteria. Two studies were conducted in Jordan and three in Egypt. These were published between 2008 and 2018. In total, 344 dyads of patients and their caregivers were recruited into the studies. The designs were two RCTs (29, 30), two non-randomized trials (31, 32) and one qualitative study (33). See table 1 for the descriptive characteristics of studies.

Insert Table 1 here

Quality Assessment

First, as shown in table (2), the methodological quality was good for Hasan, et al. (2014) and poor for Rami, et al. (2018), which has a higher risk of bias. The study was not explicit about the method of randomization or allocation concealment. Furthermore, the study protocol was not available to assess the reporting bias. The study did not provide a hypothesis, power calculation or primary outcome. All statistical differences between arms were reported, but there was no report of effort to minimise bias.

Insert table 2 here

Second, for non-randomized trials, the two studies have a high risk of bias because two or more criteria are not met according to the JBI tools (see Additional file 2 for Methodological Quality of Non-randomized Trials).

Insert table 3 here

However, there is not enough data reported to judge the quality in many instances. The study, done by Soliman, et al. (2018), was reported as a cross-sectional interventional study, but it is more consistent with quasi-experimental design because of the lack of randomisation and inclusion of control and intervention group. The study risked bias in selecting participants because the sample was not randomized. Furthermore, the drop out was not reported, which could have affected the analysis. The study by El-Shafei, et al. (2008), was reported as a case-control design but the elements of control group and randomization make it more consistent with experimental studies. They did not report the difference in basic characteristics between participants in both groups, which may have introduced a selection bias. They did not report a sample calculation and they included 30 participants only. Furthermore, no details about attrition, loss to follow-up or outcome measurement were reported.

Overall, the quality of the included studies is poor, and none of these studies, except Hasan, et al. (2014) had the statistical power to detect the benefit of family interventions. This indicates that the included studies have a risk of overestimating the effect of interventions.

Third, the qualitative study done by Al-HadiHsan, et al. (2017) is consistent with good quality studies because there was congruency between the research methodology and objectives, and the method for data collection, analysis and interpretation. However, two of the questions in the tool were answered with 'No'. The researcher did not follow any methodological theory for qualitative research because the authors were trying to answer the research question and explain the quantitative data without following specific methodological theory. (See table 4 for methodological quality of qualitative research using JBI tool).

Insert table 4 here

Intervention Characteristics

The interventions in the five studies were delivered in Egypt (3) and Jordan (2), and the content of the interventions differed across studies. All studies delivered individual family sessions, but these varied in terms of intervention characteristics like mode of delivery, duration and number of sessions. Four of the studies were delivered in a clinical setting in the outpatients' department, and one was delivered using a booklet within patients' homes. The duration of the interventions ranged from 12 weeks to 6 months. The duration of an individual session was reported in one study as 60 minutes. All the interventions were led by healthcare providers or researchers. None of the interventions were delivered in an inpatient setting. All the studies compared family interventions to standard care. See table 5 for the Intervention Characteristics Table.

Insert table 5 here

Contents and Components of the Interventions

Two studies reported the process of adaptation and modification of the original manuals (29, 30). Hasan, et al. (2014) used the framework of Atkinson and Coia, which covers Bloom's Taxonomy of Learning domains, while Rami, et al. (2018) used the Behavioural Family Therapy (BFT) manual by Mueser and Glynn (1999). The components of the interventions are in Table 6.

Insert table 6 here

First, psychoeducation components included signs, symptoms, aetiology, diagnosis, treatment, and relapse signs and management strategies for schizophrenia. Furthermore, it included truths and myths about schizophrenia, and how these affect the persons' thoughts, emotions, and behaviour. The treatment component includes information about medication, its side effects, likely benefits of the medicine, adherence to treatment, the importance of follow-up, and information regarding prognosis. Furthermore, leaflets, which contain information about schizophrenia, high expressed emotions families,

notes and homework assignments for the problem-solving and communication skills training, were distributed to participants during the sessions (Rami, et al., 2018). Second, communication enhancement training included learning skills for active listening, delivering positive and negative feedback, and requesting changes in each other's behaviours. Third, problem-solving skills training included identification of specific family problems and practical advice for solving them. Fourth, the stress vulnerability model discusses the role of the family, burden of care, and stress management skills and strategies.

Strategies Used to Adapt the Intervention

The strategies for adaptation included different themes. First, language adaptation was reported in all studies. The manuals were modified and translated into simple Arabic including folk stories relevant to the cultural beliefs of the participants. Second, the explanatory models of illness were incorporated into the adaptation process. Rami, et al. (2018) increased the number of sessions regarding the biological basis of the illness from one in the original BFT manual to two sessions because of the attribution of mental illnesses aetiology to magic and Jinn in Egyptian culture. Due to the expected low literacy levels in the Arab world, the complexity of psychoeducation was simplified, and the tools and educational material were examined for acceptability, practicality and linguistic accessibility (29, 30). Third, all the studies delivered the interventions in individual therapy sessions instead of groups to facilitate the cultural context of Arabs. Further to these adaptations, the program in Rami, et al. (2018) was shortened to 6 months instead of 9 because of practical and financial reasons that may influence adherence and attendance. See table 7 for the adaptation strategies table.

Insert table 7 here

Feasibility and Acceptability of the Interventions

Feasibility included the assessment of recruitment, attendance, retention (the proportion of participants who complete therapy sessions) and the compatibility of the interventions with the available resources. All the studies reported a feasible recruitment process without major barriers or difficulties. The attendance was also feasible because two of the studies (29, 31) delivered the interventions during the follow-up appointment, which ensured a high level of attendance. The third study by Hasan, et al. (2014) was delivered via a booklet to patients' homes. The study by El-Shafei, et al. (2008) did not report attendance. The assessment of retention was reported in two studies only (29, 30). Rami, et al. (2018) reported that four subjects from the case group and six subjects from the control group missed their regular sessions. The dropout in the Hasan, et al. (2014) study was six from the intervention group and ten from the control group. All the studies reported compatibility of the intervention with the available resources. The study by Rami, et al. (2018) reported that the intervention was applicable and accessible because of the brevity of the program. Furthermore, meeting the needs of caregivers enhanced the feasibility of the program.

Acceptability is defined as "a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention" (34). Hasan, et al. (2014) followed his trial with a qualitative study to assess the acceptability of interventions. The qualitative interviews with service users and caregivers confirmed the acceptability of the interventions. They found that interventions using booklets was appropriate and valuable. No other studies examined acceptability.

Effect of Interventions

The outcomes reported across the studies vary a great deal and most of them did not distinguish primary from secondary outcomes. The most frequently reported primary and/or secondary outcome is severity of symptoms using the Positive and Negative Syndrome Scale (PANSS). The four studies found a statistically significant difference between the two groups concerning positive and negative symptoms experienced by service users, favouring the intervention group. Furthermore, Hasan, et al. (2014) found a reduction in the severity of symptoms at three months follow-up. Other frequently reported outcomes were social functioning, adherence to medication, quality of life and knowledge of schizophrenia. One study only assessed family outcomes including family burden of care and carers' quality of life. (See Table 8 for the results of each outcome).

Insert table 8 here

Discussion

The present systematic review is the first to synthesise the available evidence about culturally-adapted family interventions for schizophrenia in the Arab world. The findings indicated a paucity of local studies to guide the ongoing development of family interventions in this area. Egypt and Jordan are the only two countries from the 22 countries in the Arab world that have published peer-reviewed papers on this topic. It is widely acknowledged that the Arab region has limited local research to guide the culturally appropriate development of different services in mental health (23, 35). The mental health status in the Arab world is still low compared to industrialized countries because the health and education budget is still below requirements (24). Furthermore, Okasha, et al. (2012) found in their summary about mental health services in the Arab world that some Arab countries do not have mental health legislation, and some do not even have mental health policies. In addition, most of the countries have less than 30 psychiatric beds per 100,000 of the population. Therefore, the insufficient resources and services, and lack of research capability to enhance capacity for conducting high-quality research, gives an indication of the amount and quality of research in this area (24, 36). The cultural adaptation process of family interventions in the Arab world was consistent with some of the themes found in previous studies including language, content, concepts and illness models, cultural norms and practice, context and

delivery (11, 13, 14). The language of the original manuals was translated into Arabic and the content was modified to fit the cultural and religious norms and values. The language was simplified using classic Arabic and folk stories to fit the expected low level of literacy. This review identified two Arabic translated and adapted manuals that can be used in future studies in the Arab world with minimal modification depending on the specific country's norms and traditions. Regarding the context and delivery, the interventions were mainly delivered in a clinical setting, which could be explained by the underdevelopment of community mental health in the Arab world (24). Furthermore, the number of sessions about the biological basis of the illness were increased because most Arab people believe strongly in the existence of supernatural reasons like black magic and Jinn, and they usually relate mental illness symptoms to these reasons (22). However, the most interesting finding was that all the interventions were single-family format. The possible explanation could be the stigma and discomfort Arabic people feel about discussing the details of their relatives in front of other families in a group. The stigma about mental illness is worldwide, but it is stronger in the Arab world because they value group harmony and a group mind-set which is opposite to western countries, which value individual autonomy (37). The stigma attached to mental illness in the Arab world is one of the important factors that could negatively impact access and utilization of mental health services (38). The stigma is embedded in Arabic culture, making it difficult to develop and test interventions for individuals and their families (22). Therefore, it is not surprising that Arabic people would shy away from seeking help from mental health professionals. The adaptation process was comprehensive, including piloting the intervention to examine its acceptability and language simplicity and modifying the content accordingly before starting the actual study. This element was congruent with most of the developed culturally-adapted interventions to ensure the usefulness and efficacy of delivering the intervention (13, 39). Another element of adaptation was providing the participants with leaflets that contain the main information learned in each session. This technique ensures the reinforcement of learning and the spreading of information to other members of the family or even to the community. However, this was in contrast with the findings from the systematic review by Chowdhary, et al. (2014), where they try to use non-written material to simplify the information. In the Arab world, it could be more helpful to use non-written material like videos and so on because of the low level of literacy. It seems from the review that the adaptation process for family interventions seems robust because it is congruent with the themes from the previous systematic reviews. Furthermore, it gives a clear indication that such interventions are feasible and acceptable enough to be applied in Arab countries. Assessing the effectiveness of the interventions was not a major objective of this review. Even if we wanted to do so, the evidence is not available, mainly because of the poor methodology of the included studies. The studies showed a positive effect favouring the intervention groups in different outcomes, such as the severity of symptoms, quality of life for service users and their caregivers, social function, the adherence to medications and knowledge of schizophrenia. The severity of symptoms using the Positive and Negative Syndrome Scale (PANSS) was a common outcome measure used in all studies. Even though the studies showed a positive impact on different outcomes, which is in agreement with previous systematic reviews (9, 13, 14), the findings may not be valid because of the size and poor quality of the included studies. The quality of the included studies was poor, and none of these studies, except Hasan, et al. (2014) had the statistical power to detect a difference in the primary outcome identified.

Furthermore, the review included studies that were diverse in design, types of interventions and outcomes, in addition to a small number of studies. All these reasons make meta-analysis impossible. It is difficult to ensure the effectiveness of such interventions in the Arab world with the available literature. Therefore, more work is needed in the Arab world using high-quality research designs and methods with rigorous procedures. One strength of this review is that participants were from a similar culture in the Arab world, and spoke the same language, which could be unique compared to previous systematic reviews that included several cultures (9, 14). Furthermore, the process of searching was thorough, and the protocol was rigorously followed for study selection, data extraction, analysis and synthesis. However, the small number of included studies are variable in design, characteristics and components of the interventions. This restricted the conclusion regarding the different objectives of the review. Furthermore, there was little distinction between primary and secondary outcomes of the included studies, which caused confusion and made it difficult to interpret whether the treatment effect differed across outcomes. This review could be part of a body of literature that is relevant to the needs of Arabic people worldwide and it will inform the development of family interventions for relatives living with schizophrenia in Oman. Furthermore, it could facilitate future research into effective interventions and provide much-needed resources for implementing family interventions for Arabic people globally.

Conclusions

This study set out to identify the content and characteristics of culturally-adapted family interventions in the Arab world and to determine the strategies used for adaptation. Furthermore, it aimed to assess the feasibility, acceptability and effectiveness of these interventions. The present review provides the foundation for future work about family interventions in the Arab world. It provides guidance for the translated manual and tools for different outcomes. Furthermore, the adaptation process seems robust, but the rigour of testing is largely absent. The attempts are still fragmented, so a systematic process of developing and evaluating such interventions should be applied in order to benefit a larger proportion of the Arabic population. The Arab world has scarce resources, and the experience of mental illness is complicated by the disadvantages of war, poverty and the stigma attached to mental illness. Therefore, culturally-adapted family interventions for schizophrenia have the potential to improve the mental illness experience of Arabic people globally. It is recommended that further research, using a more suitable methodology, is carried out in order to establish and gain a better understanding of the possible effectiveness of such interventions in Arabic countries.

Abbreviations

RCT: randomized control trial

LMICs: low and middle income countries

GCC: Gulf Cooperation Council

PROSPERO: prospective register of systematic reviews

ICD-10: International Classification of Diseases -10

JBI: The Joanna Briggs Institute

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PANSS: Positive and Negative Syndrome Scale

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

AA run the databases search, obtained the articles, extracted the data, critically appraised them, analysed and interpreted the data and was a major contributor in writing the manuscript. KL , LR & NH contributed to the conception and design of the work and substantively revised the manuscript. All authors read and approved the final manuscript

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Tables

Due to technical limitations, tables are only available as a download in the supplemental files section

Figures

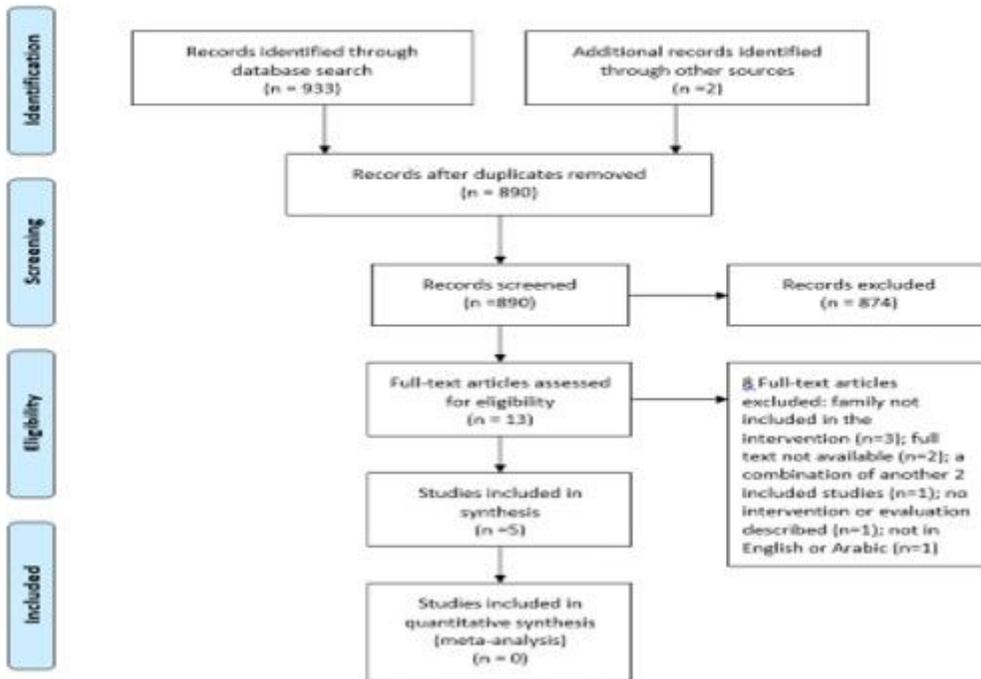


Figure 1

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) flow chart describing the study selection process along with the reasons for exclusion.

Supplementary Files

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