

CULTURALLY-ADAPTED FAMILY INTERVENTION (CAFI) FOR AFRICAN-CARIBBEAN PEOPLE DIAGNOSED WITH SCHIZOPHRENIA AND THEIR FAMILIES: A MIXED-METHODS FEASIBILITY STUDY OF DEVELOPMENT, IMPLEMENTATION AND ACCEPTABILITY

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Declared competing interests of authors: All authors confirm they have no conflicts of interest to declare.

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Key Words: Schizophrenia, Psychosis, African-Caribbean, Family Intervention, cultural-adaptation, Culturally-adapted Family Intervention (CaFI), Ethnicity, culture, mixed-methods research.

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The research reported in this 'first look' scientific summary was funded by the HS&DR programme or one of its predecessor programmes (NIHR Service Delivery and Organisation programme, or Health Services Research programme) as project number 12/5001/62. For more information visit <https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/12500162/#/>

The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PHR editors have tried to ensure the accuracy of the authors' work and would like to thank the reviewers for their constructive comments however; they do not accept liability for damages or losses arising from material published in this scientific summary.

This 'first look' scientific summary presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the PHR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PHR programme or the Department of Health.

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SCIENTIFIC SUMMARY

Background

Compared with other ethnic minorities, African-Caribbeans in the UK have the highest schizophrenia incidence and greatest inequity in access to mental healthcare. NICE schizophrenia guidance highlights the urgent need to improve evidence-based mental healthcare, experiences of services, and outcomes for this group. Family Intervention (FI) is clinically and cost-effective for the management of schizophrenia, reducing the risk of relapse and hospitalisation. However, FI is rarely offered particularly to minority groups. This is despite NICE recommendations that FI should be offered to all service users in regular contact with their families. As African-Caribbeans are especially likely to lose contact with their families, they are less likely than other groups to be offered FI. The evidence for FI with minority ethnic groups generally, and African-Caribbeans in particular, is lacking. We therefore do not know whether FI would be as effective in this group as in predominantly White samples with whom it has been trialled.

Aims and objectives

The study had two over-arching aims:

1. Assess the feasibility of culturally-adapting, implementing and evaluating an innovative approach to FI among African-Caribbean service users with schizophrenia and their families across a range of clinical settings.
2. Test the feasibility and acceptability of delivering FI via 'proxy families' where biological families are not available.

The study objectives were to:

- i. Involve key stakeholders (service users, families and clinicians) in culturally-adapting an existing family intervention for African Caribbeans with schizophrenia.
- ii. Produce a manual to support delivery of the intervention.
- iii. Identify client and family centred outcomes and quality of life outcomes
- iv. Identify and address the training needs of therapists and 'proxy families'.
- v. Test feasibility of delivering culturally-adapted FI among African Caribbeans in hospital and community settings.

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- vi. Test feasibility of recruiting biological and 'proxy families' and delivering the intervention via both.
- vii. Test the feasibility of recruiting participants in hospital and community settings
- viii. Compare recruitment and retention in different clinical settings
- ix. Identify outcome measures for future randomised studies and assess the feasibility of collecting them.
- x. Assess acceptability of the intervention with key stakeholders – service users, their families and mental health professionals.

Methods

A feasibility cohort design, incorporating qualitative components was undertaken in two mental health trusts in the North-West of England. The study was divided into three main phases:

Phase 1: Culturally-adapting the FI using qualitative methods (Focus Groups (1B) and Consensus Conference (1C)) underpinned by the literature (1A).

Phase 2: Developing and delivering training for therapists and Family Support Members (FSMs) / *'Proxy Families'*.

Phase 3: A feasibility study, incorporating methods to assess a) therapists' fidelity to the therapy manual and b) the acceptability of the intervention to key stakeholders (African-Caribbean service users, their families, FSMs, and health professionals).

We used a range of innovative methods to recruit key stakeholders to co-produce a Culturally-adapted Family Intervention (CaFI). In focus groups (n=42), we rigorously applied a cultural-adaptation framework derived from our systematic review to identify the essential elements needed to culturally-adapt the structured, cognitive-behavioural model of FI developed by co-investigators Barrowclough and Tarrier. A consensus panel of (n=22) 'experts' by experience and profession agreed the final set of culturally-specific components of the intervention. They also identified therapists' and FSM's training needs. We used this information to develop therapy and training manuals.

A convenience sample (n=31) was recruited to assess the feasibility of delivering CaFI across acute, rehabilitation, and community settings and via FSMs where biological families were not

available. Family units (service users, families and/or FSMs) received 10 CaFI sessions within a 20-week therapy window. Key outcomes were:

- Recruitment (number approached versus number consented)
- Attendance (number of sessions attended)
- Attrition (number of drop-outs at each time point)
- Retention (the proportion of participants who complete therapy sessions)
- Completeness of outcome measurement

We tested the feasibility of collecting a range of service user, family, and service outcomes and to establish the parameters for a future RCT. Acceptability and fidelity data were collected via feedback sheets at each session and qualitative interviews within three months of the end of therapy.

Results

CaFI sessions were co-delivered by pairs of therapists who had received two days of training in cultural competence and family working skills and further half-day training in using the CaFI manual effectively. Of 74 eligible service users, 31 (42%) consented into the feasibility trial. The majority (n=21, 67.7%) were recruited from community settings. They were predominantly male (n=21, 67.7%) with a mean age of 43 (Range: 17 – 81, SD=13.77). The majority were born in England (n=22, 78.57%) and had religious affiliations (n=22, 81.48%), principally Christian (n=17, 77%). Although 23 (85.19%) service users held GCSE or higher qualification, more than (51.85%) were 'long-term sick' or registered disabled. None were employed. Among service users who started CaFI (n=26), 13 (50%) elected to do so with family members. The remainder were supported by FSMs.

Twenty-four of 26 family units (92%) that commenced CaFI completed all ten sessions. The numbers who completed treatment as a proportion of those who consented was 77.42% (24 out of 31). The mean number of sessions attended by family units (i.e. the service user, relative/FSM or both) was 7.90 (SD 3.96) out of ten. It proved feasible to collect a range of other outcome data at baseline, post-intervention and at three-month follow-up. For example, we collected PANSS for 96% of service users at baseline, 100% post-intervention and 100% at 3-month follow-up.

Fidelity to the therapy manual was good. Therapists generally delivered therapy to protocol using core skills in CBT for psychosis as well as cultural competency. Despite self-rated improved confidence in cultural competency following training, non-psychologists reported lack of confidence in practice. This, coupled with reports of increasing workloads, might partly account for findings that they were more likely than psychologists to breach the 20-week therapy window. Nevertheless, our study demonstrated both the feasibility and acceptability of delivering CaFI via non-psychologists.

Rating of sessions and qualitative findings indicated that CaFI was acceptable to service users, their families, FSMs, and healthcare professionals. Over 80% of service users agreed they learned something new during CaFI, knew more about where to get information, had a better relationship with their relatives and were more able to say what their needs were. Three-quarters felt mostly positive about the sessions and almost 90% said the one-hour session was about the right length. From service users' perspectives, perceived benefits included:

- Increased confidence and self-esteem
- Greater insight into illness
- Improved symptoms
- Improved knowledge and understanding of services
- Better communication with family and health professionals
- Improved coping skills including

Asked if they would recommend CaFI to someone else, this service users' view typified responses:

"I would do, yeah. I really would, I really would. I think it should get spread all over the United Kingdom. I think it really should, 'cause I think it's really helpful. It's helped me a lot." (SU521)

Conclusions

We have demonstrated the feasibility of culturally-adapting, implementing, and evaluating family intervention (FI) in partnership with African-Caribbean service users, their families, community members, and healthcare professionals. Given that African-Caribbeans' engagement with mental health services has been characterised by fear, mistrust, and avoidance for many decades this is a significant achievement.

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An important finding from our acceptability study was the view that CaFI should be rolled out across the NHS and should be made available to all ethnic groups versus limiting its perceived benefits to African-Caribbeans. Our findings indicate that this would require capacity-building and increased resource to provide enough suitably qualified therapists and supervisors to deliver culturally-competent therapy. Our findings also indicate that a cultural competency framework to evaluate therapists' skills represents a significant gap in clinical practice.

Given that we have demonstrated the feasibility of culturally-adapting and testing FI with arguably the most challenging service user group, it should be possible to do so for other groups. However, participants suggested that it is neither practical nor financially viable to implement different culturally-adapted versions of FI for each ethnic/cultural group in the UK. Instead, a *culturally-adaptable* form is advocated. This requires further work to ensure that resulting interventions have broad appeal across ethnic minorities groups and are cost and clinically-effective. In this context, working with FSMs where no biological families are available is worthy of further exploration. Fully-powered studies are necessary to evaluate the effectiveness of modifying FI in this way. In light of the increasing diversity of the UK population, this seems an attractive proposition for meeting the needs of the population and would mark an important development in tackling seemingly entrenched ethnically-based inequalities in access to evidence-based psychosocial interventions.

Implications for healthcare

- Our study provides evidence that it is feasible to culturally-adapt and implement FI with arguably the most difficult to engage service user group. This suggests it should be possible to develop similar interventions with others.
- NICE recommends FI. Steps should be taken to ensure that FI is culturally-appropriate so meeting the needs of all sections of society.
- Current guidelines indicate that FI need only be offered to people with families. As demonstrated by our study, this would mean that around half of some groups of service users with the greatest need would not be eligible to receive FI.
- Whilst FI has a strong evidence base, this is not yet the case for culturally-adapted interventions like CaFI. This is important because commissioners require evidence of cost and clinical-effectiveness to determine whether specifically culturally-adapted FI is warranted or, as has been suggested by our study participants, more *culturally-adaptable* approaches should be commissioned.

- Delivering person-centred care in a multi-cultural context requires new service provision, especially in an economically challenged NHS. For example, unlike African-Caribbeans who are an established group, many recent migrants to the UK have experienced significant levels of trauma, often arriving in the UK without families. Meeting their needs will require a highly-skilled and responsive workforce together with novel approaches such as working with FSMs.
- Our findings suggest there is potential for FSMs (particularly key workers/care coordinators) to participate in delivery of FI. Community-based FSMs might facilitate reconnection of services users with their families and communities. This might be especially salient for recent migrants fleeing conflict and other marginalised groups.
- Delivering FI in a multi-cultural context requires effective cultural competence training and measures to demonstrate proficiency. What this would look like and how it can be sustained in a financially-straitened NHS requires investigation based on further evidence of cost and clinical-effectiveness effectiveness.
- Developing expertise to effectively deliver culturally-adaptable psychological interventions by a wider range of healthcare professionals appears to be an imperative.
- Low cost psychological interventions that can be developed in future may include educational and culturally-adapted service materials to support embedding culturally-appropriate approaches in routine practice.
- The availability of accurate ethnicity data and clinical information such as relapse indicators is urgently needed in services.

RESEARCH RECOMMENDATIONS

- 1) Test the CaFI model in multi-centre trial. Our study proved feasible in central Manchester. As population demographics, service models and commissioning practices vary across the country, research is needed to assess its clinical and cost-effectiveness in a range of different contexts. Including process evaluation and implementation science to identify barriers to implementation and strategies to overcome them within a trial would enable us to evaluate the feasibility of embedding CaFI in routine practice across the country without the need for further preparatory work.

- 2) High levels of engagement and trust-building were integral to our success in recruiting and retaining participants despite organisational challenges. We recommend that this approach is replicated and fully costed in future trials.
- 3) Trial CaFI alongside culturally-adapted versions for other ethnic groups. As recommended by our stakeholders, developing a '*culturally-adaptable*' model makes good sense in a multi-cultural society. Trials involving other ethnic groups could identify the key components that constitute a robust culturally-adaptable model. Such a model could potentially have international utility.
- 4) Develop a proficiency framework to assess cultural competence. Despite bespoke training delivering self-reported improved cultural awareness and confidence, this was not borne out in practice. This suggests that a framework to assess cultural proficiency is needed.
- 5) Further work is needed to examine the role of FSMs without whom; half the service users in our study would not have been able to access CaFI. Although delivery via care coordinator/key worker FSMs was positively evaluated, for example enabling service users to address difficulties in relation to their care, our findings suggest that involvement of FSMs may be a related but different intervention from extant FI. Process evaluation and further work to understand the mechanisms of this aspect of the intervention within a trial would help to determine how the role of FSMs might be developed and deployed, for example, using peer support workers alongside care coordinators/key workers. Undertaking this work within a trial, would also help to determine whether FSMs would prove cost and clinically-effective and therefore commissionable as part of an innovative approach to service delivery.