

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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Scientific summary

CaFI for African-Caribbeans diagnosed with schizophrenia

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Scientific summary

Background

Compared with other ethnic minorities, African-Caribbean people in the UK have the highest schizophrenia incidence and the greatest inequity in access to mental health care. The National Institute for Health and Care Excellence (NICE) schizophrenia guidance highlights the urgent need to improve evidence-based mental health care, experiences of services and outcomes for this group. Family intervention (FI) is clinically effective 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 who are in regular contact with their families. As African-Caribbean people 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-Caribbean people in particular, is lacking. We therefore do not know if FI would be as effective for this group as it has been for the predominantly White samples in which it has been trialled.

Aims and objectives

The study had two overarching aims:

1. to 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. to test the feasibility and acceptability of delivering FI via 'proxy families' where biological families are not available.

The study objectives were:

- i. to involve key stakeholders (service users, families and clinicians) in culturally adapting an existing family intervention (FI) for African-Caribbean people with schizophrenia
- ii. to produce a manual to support the delivery of the intervention
- iii. to identify client- and family-centred outcomes and quality-of-life outcomes
- iv. to identify and address the training needs of therapists and 'proxy families'
- v. to test the feasibility of delivering the Culturally adapted Family Intervention (CaFI) to African-Caribbean people in hospital and community settings
- vi. to test the feasibility of recruiting biological and 'proxy families' and delivering the intervention via both
- vii. to test the feasibility of recruiting participants in hospital and community settings
- viii. to compare recruitment and retention in different clinical settings
- ix. to identify outcome measures for future randomised studies and assess the feasibility of collecting them
- x. to assess the 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 north-west 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 (1) therapists’ fidelity to the therapy manual and (2) 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 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 FSMs’ 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. The key outcomes were:

- recruitment (number approached vs. number consented)
- attendance (number of sessions attended)
- attrition (number of dropouts 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 randomised controlled trial. Acceptability and fidelity data were collected via feedback sheets at each session and qualitative interviews within 3 months of the end of therapy.

Results

The CaFI sessions were co-delivered by pairs of therapists who had received 2 days of training in cultural competence and family working skills and a further half-day of training in using the CaFI manual effectively. Of 74 eligible service users, 31 (42%) consented to take part in the feasibility trial. The majority ($n = 21$, 67.7%) were recruited from community settings. They were predominantly male ($n = 21$, 67.7%) and had a mean age of 43 years [range 17–81 years, standard deviation (SD) 13.77 years]. The majority were born in England ($n = 22$, 78.57%) and had religious affiliations ($n = 22$, 81.48%), principally Christian ($n = 17$, 77%). Twenty-three (85.19%) service users held a General Certificate of Secondary Education (GCSE) or higher qualification, and more than half (51.85%) were ‘long-term sick’ or registered disabled. No service users were employed. Of the service users who started CaFI ($n = 26$), 13 (50%) elected to do so with family members and the remainder were supported by FSMs.

Twenty-four out of the 26 family units (92%) that commenced CaFI completed all 10 sessions. Those who completed treatment as a proportion of those who consented was 77.42% (24/31). The mean number of sessions attended by family units (i.e. the service user, relative/FSM or both) was 7.90 (SD 3.96 sessions) out of 10. It proved feasible to collect a range of other outcome data at baseline, post intervention and at

the 3-month follow-up. For example, we collected Positive and Negative Syndrome Scale data for 96% of service users at baseline, for 100% post intervention and for 100% at the 3-month follow-up.

Fidelity to the therapy manual was good. Therapists generally delivered therapy to protocol using core skills in cognitive-behavioural therapy for psychosis as well as in 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 health-care professionals. Over 80% of service users agreed that 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 that the 1-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 to ability to draw on personal and community resources.

Asked if they would recommend CaFI to someone else, this service user's 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.

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Conclusions

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

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 rather than limiting its perceived benefits to African-Caribbean people. Our findings indicate that this would require capacity building and increased resources 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 minority groups and are cost-effective 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 the 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 health care

- 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 that it should be possible to develop similar interventions with others.
- NICE recommends FI. Steps should be taken to ensure that FI is culturally appropriate, and so meets the needs of all sections of society.
- Current guidelines indicate that FI needs to be offered only 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.
- Although FI has a strong evidence base, this is not yet the case for culturally adapted interventions such as CaFI. This is important because commissioners require evidence of cost-effectiveness 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 multicultural context requires new service provision, especially in an economically challenged NHS. For example, unlike African-Caribbean people, who are an established group, many recent migrants to the UK have experienced significant levels of trauma and often arrive 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 that there is potential for FSMs [particularly key workers/care co-ordinators (CCs)] 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 multicultural 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 strained NHS requires investigation based on further evidence of cost-effectiveness and clinical effectiveness.
- Developing the expertise of a wider range of health-care professionals to enable them to effectively deliver culturally adaptable psychological interventions 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. The CaFI model should be tested in a multicentre 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 clinical effectiveness and cost-effectiveness of CaFI 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 be 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 multicultural society. Trials involving other ethnic groups could identify the key components that constitute a robust culturally adaptable model. Such a model has the potential for international utility.
4. Develop a proficiency framework for health professionals to assess cultural competence. Despite bespoke training in 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 of the service users in our study would not have been able to access CaFI. Although delivery via CC/key worker FSMs was positively evaluated (e.g. enabling service users to address difficulties in relation to their care), our findings suggest that the 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 (e.g. using peer support workers alongside CCs/key workers). Undertaking this work within a trial would also help to determine whether or not FSMs would prove cost-effective and clinically effective and, therefore, commissionable as part of an innovative approach to service delivery.

Trial registration

This trial is registered as ISRCTN94393315.

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