

CaFI

Culturally-adapted
Family Intervention
African Caribbean service users & families

Expert Consensus Study
Thursday 20th March 2014

Dawn Edge – Principal Investigator
John Baker – Co-Investigator
Amy Degnan – Research Project Manager



Agenda for the day

Administration and tea/ coffee in the Hub	9:30am
Welcome, introductions and overview of the day	10:00am
Project and consensus study overview	10.10am
Session 1: CaFI Content	10:30am
Comfort break in the Hub	11.15am
Session 2: CaFI Outcomes	11.30am
Lunch in Mumford Restaurant	12:45pm
Session 3: CaFI Delivery	1.30pm
AoB & Summary	2.45pm
Close	3:00pm

This project was funded by the National Institute of Health Research Health Service and Delivery Research Programme (project number 12/0001/02). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the Health Service and Delivery Research Programme, NHS, NHS or the Department of Health.

Research Team

Co-applicants:

Dr Dawn Edge	Miss Amy Degnan	Rev Paul Grey
Dr Richard Drake	Dr John Baker	Dr Katherine Berry
Dr Sarah Cotterill	Mr Patrick Cahoon	Prof Kathryn Abel
Prof Shon Lewis	Prof Dinesh Bhugra	Prof Nicholas Tarrier
Prof Christine Barrowclough		

Collaborators:

Mrs Daisy Barrett	Dr Mark Harrison	Dr Judith Richardson
Prof Karina Lovell	Dr Nusrat Hussain	Prof Kevin Ronan
Dr Alicia Moxon	Ms Yvonne Thomas	Ms Natasha Peniston
Mrs Mary Maynard	Connect support	GM Neighbourhood Police
Meriden Family Programme	African Caribbean Mental Health Services	

With thanks to...

Black and Asian Police Association, Just Psychology, Support4Progress, Rethink, Manchester Carers Forum, Manchester Carers Centre, BME Network, BlueSci, MHRN, PeopleInResearch Forum, Black Health Agency, NICE, Centre for Mental Health, Race Equality Foundation, Peace FM and more!

‘There is no such thing as African Caribbean culture’



There is no such thing as African Caribbean culture?

- A. True
- B. False



28/02/2017

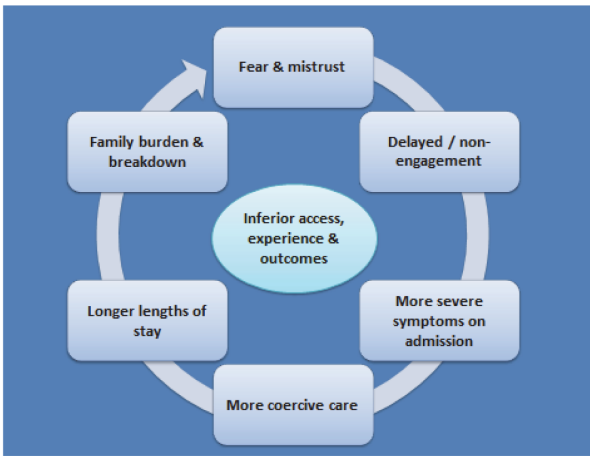
Background

African Caribbeans in UK greatest inequalities in access, experiences and outcomes than any other ethnic group

➔ Rates of schizophrenia higher than White British
Manchester 1.7% population but 16.5% inpatients

NICE guidelines (2009) recommend Family Intervention (FI) for schizophrenia

➔ Engaging patients and families improves outcomes
FI clinically and cost effective but patients rarely offered it
Lack of psychological therapies for African Caribbeans



MANCHESTER 1824 Manchester Mental Health and Social Care Trust NHS

CaFI Study Aims

1. To assess the feasibility of culturally-adapting, delivering and evaluating a new family therapy (CaFI) for African Caribbeans with schizophrenia and their families across a range of clinical settings.
2. To test the feasibility and acceptability of delivering CaFI via 'proxy families' where biological families are not available.

MANCHESTER 1824 Manchester Mental Health and Social Care Trust NHS

Project Plan: Phase 1

Phase 1 (mths 0-9)
Culturally-adapting Family Intervention

1A Literature review

1B Focus groups

- 1) health professionals (n=7), 2) service users (n=10), 3) carers & advocates (n=14)
- Mixed group (n=11)

1C Consensus conference

- n=21: key 'expert' stakeholders

MANCHESTER 1824 Manchester Mental Health and Social Care Trust NHS

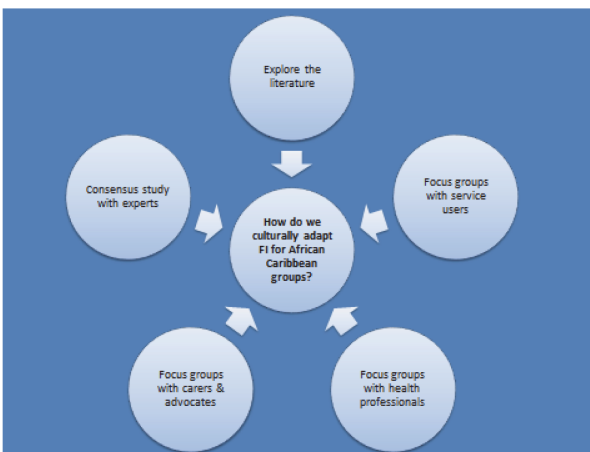
Project Plan: Phase 2 & 3

Phase 2 (mths 10-14)
Training

- Family therapists & co-therapists – delivery CaFI
- Proxy families – supportive role in CaFI
- Cultural competency seminars for NHS staff (x3, 1 per year)

Phase 3 (mths 15-32)
Feasibility Study: Delivering & Evaluating CaFI

- Recruit (n=30) AC service users 'schizophrenia' and/or families
 - Rehab wards, acute wards, CMHTs (n=10 each)
- Deliver approx 10 x 1-2 hour long CaFI sessions
 - Psycho-education, stress management, problem-solving
- Collect outcome data



MANCHESTER 1824 Manchester Mental Health and Social Care Trust NHS

Phase 1C: Consensus Study

- Expert stakeholders will synthesise data:
 - Phase 1A – Literature review
 - Phase 1B – Focus Groups
- Identify essential elements for culturally-adapting model of **Family Intervention (FI)**; Barrowclough & Tarrier, 1992)
- Key focus FI = Changing attributions in order to effect behaviour change to create more supportive family relationships

How do we reach consensus?

- 'Consensus' arrived through process of facilitated open discussion and debate
- Explore areas of agreement and disagreement
- Reach '*near unanimous*' agreement
- Residual areas of disagreement resolved by:
 - Research Management Group
 - Research Advisory Group
 - Expert reviewers



Consensus Study: Session 2

- Identify key *outcome measures* relevant and important for African Caribbean groups.
- Agree on outcomes to *inform data collection* and help refine *delivery and evaluation* of CaFI (Phase 3)
 - Service users
 - Families & carers
 - Health professionals



Session 1: CaFI Content

Summary Focus Group findings:

- Family Intervention (FI) model well received
- African Caribbean specific changes:
 - Additional relevant topics
 - Different ethos & delivery
 - Therapeutic competency & training

Current FI model:

1. Service user assessment
2. Family assessment
3. Psycho-education
4. Stress management and coping
5. Problem solving and goal planning

Consensus Study: Session 1

- Adapt FI *content* to make more culturally appropriate for African Caribbean groups
- Agree *specific topics* to be included in CaFI manual in the five key FI components:

1. Service user assessment
2. Family assessment
3. Psycho-education
4. Stress management and coping
5. Problem solving and goal planning



Consensus Study: Session 3

- Adapt the *delivery* of FI to meet the particular needs of African Caribbean groups
- Agree on *key issues to support delivery* of CaFI
- To inform CaFI training manual

Service user assessment

Four sections:

- 1) Current & past episode of illness
- 2) Functioning
- 3) Strengths & resources
- 4) Relationships

Service user assessment

1) Current and past episodes

Current model:

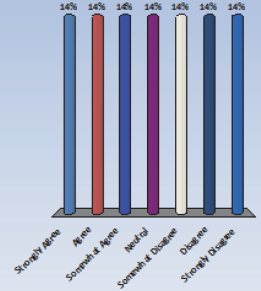
- Main symptoms/experiences
 - e.g. hearing voices that others cannot hear, delusions, lack of motivation, low mood, not wanting to socialise
- What makes symptoms better/worse
- Treatment and other ways of managing symptoms
 - What worked?
 - What didn't?

Specific to African Caribbean:

- Racism (as trigger for illness): AC living in white society
 - Perceptions, beliefs and experiences
 - Problems at school/adulthood
 - Bullying, harassment
- Fear → Avoidance of services/help-seeking:
 - Service User: diagnosis
 - Others' fear of SU: Family, community members, professionals
- Spirituality and belief systems
- Wellness and wellbeing
- Previous experiences of services: helpful & unhelpful; positive & negative
- Medication & side effects e.g. weight gain (linked to stigma)

These items improve the relevance of the service user assessment for African Caribbean people

- A. Strongly Agree
- B. Agree
- C. Somewhat Agree
- D. Neutral
- E. Somewhat Disagree
- F. Disagree
- G. Strongly Disagree



Service user assessment

2) Functioning

Current model:

How the illness affects service user's ability to function (day-to-day living) ability to do everyday things.

Impact of symptoms on social & occupational functioning:

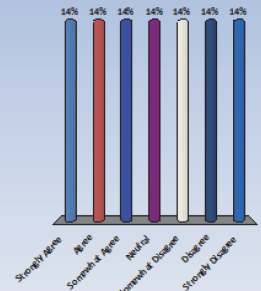
- Getting out of the house/flat
- Being around people
- Shopping, cleaning
- Personal hygiene
- Decision making
- Make plans
- Sleep patterns → impact on daily life
- How spend time: meaningful activity, work, volunteering

Specific to African Caribbean:

- Place/role/perceptions in community
 - Social functioning
 - Social isolation/loneliness/withdrawal
- Vision and purpose
 - Hope for the future
 - Personal aspirations
- Managing money
- Diet and nutrition
 - Access to 'healthy foods' (not stereotypical)

These items improve the relevance of the service user assessment for African Caribbean people?

- A. Strongly Agree
- B. Agree
- C. Somewhat Agree
- D. Neutral
- E. Somewhat Disagree
- F. Disagree
- G. Strongly Disagree



Family Assessment

Current model:

The relative's beliefs and attitudes about the illness:

- Cause and maintenance of symptoms
- Views on treatments e.g. medication and how to manage illness at home

Distress in relatives and situations, including thoughts that trigger distress.

Dealing with service user's experiences and difficulties and how these affect the service user and family members.

The impact of the illness on the relative, including any restrictions hardships and difficulties.

The relative's relationship with the service user – how they get on together

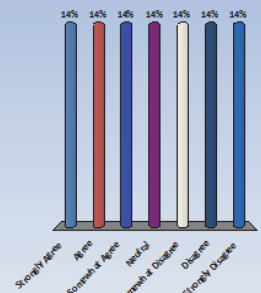
Areas of strength and effective coping strategies

Specific to African Caribbean:

- Family structure, hierarchy
- Tension in family: blame, criticism, accusations, rivalry
- Previous experience of services – helpful and unhelpful
- Hopes and aspirations

These items improve the relevance of the service user assessment for African Caribbean people?

- A. Strongly Agree
- B. Agree
- C. Somewhat Agree
- D. Neutral
- E. Somewhat Disagree
- F. Disagree
- G. Strongly Disagree



Psycho-education

Current model:

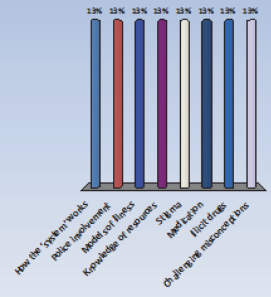
- Understanding schizophrenia (symptoms, functioning)
- Current illness models
- Current treatments available
- Beliefs about the illness 'helpful' vs. 'unhelpful'
 - *Controllability* – extent to which service users can control symptoms (e.g. difficult behaviour is controllable)
 - *Responsibility* – extent to which patient is responsible for their symptoms
 - *Criticism* (e.g. 'he's lazy – he won't get out of bed')

Specific to African Caribbean:

- How mental health 'system' works
- Police involvement including differences between UK & Caribbean
- Models of illness
- Knowledge of resources e.g. support groups, hearing voices movement
- Impact of stigma (normalising symptoms/illness to reduce) – inc. in the media
- Medication: how it affects the brain, side effects, physical effects, anxiety
- Illicit drugs e.g. Cannabis use: use as self-medication, challenge stereotype
- Challenging misconceptions e.g. mental illness as weakness/deviance

Choose three items you consider the most important for psycho-education

- How the 'system' works
- Police involvement
- Models of illness
- Knowledge of resources
- Stigma
- Medication
- Illicit drugs
- Challenging misconceptions



Stress Management and Coping

Current model:

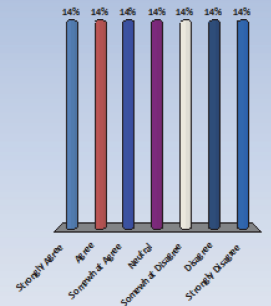
- Current stress in the family
- Service-user focused situations that are difficult to cope with (e.g. aggressive behaviour and suicide risk)
- Stress management
 - Current helpful/unhelpful ways of coping with stress
 - Resources and strengths for helping to manage stress (e.g. Social support, leisure interests, relaxation training)
- Self-monitoring
- Monitoring daily stressors, stressful situations and ways of coping (e.g. diary)
- Changing unhelpful ways of dealing with stress
 - Relatives' unhelpful beliefs about behaviours & unrealistic expectations (e.g. trying to change delusional beliefs/voice hearing through arguments or threats)

Specific to African Caribbean:

- Conflict:
 - Sectioning relatives
 - With professionals re. involvement in care
- Acknowledging role as carer and carer burden
- Carer rights and responsibilities
- Positive ways of coping – turning negative to positive
- Resources available e.g. 'dialogue with voice'
- Boundary setting
 - Responsibilities/roles in managing illness → reducing dependence, control
- Realistic expectations from family members
- Two-way support (family and service user)
- Crisis planning – coping strategies when sectioned etc.
- Relapse prevention – how to detect and manage early warning signs

These items improve the relevance of the service user assessment for African Caribbean people?

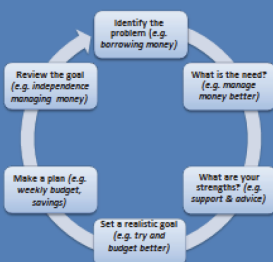
- Strongly Agree
- Agree
- Somewhat Agree
- Neutral
- Somewhat Disagree
- Disagree
- Strongly Disagree



Problem solving & goal planning

Current model:

10 steps that the service user, therapist and the family work through to achieve the goals they agree and work through them using this cycle:



Specific to African Caribbean:

- People generally thought this was a good approach. Liked breaking goals into small, achievable steps (a process).
- Highlights resources an solutions to problems – confidence building
- Contingency plans: Being explicit about what happens if someone becomes ill/goals not achieved
- Negotiated rewards for achieving goals – celebrating success
- Focus on progress rather than failure – positive mental attitude
- Some people thought diagram unhelpful (suggests going round and round) – suggested using flow diagram, different format to suit family's preferred learning style (choice)

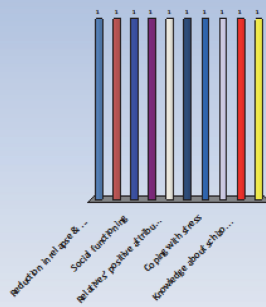
Consensus Study: Session 2

- Agree on primary and secondary *outcome measures* relevant and important for African Caribbean groups.
- Rank outcomes identified as important from the focus groups:
 - Service users
 - Families & carers
 - Health professionals
- Refer to 'CaFI outcomes' sheet for details
- Discuss in groups before ranking



Please rank the following items from *most* (1) to *least* (10) important

- A. Reduction in relapse & readmission
- B. Less reliance on medication
- C. Social functioning
- D. Health and wellbeing
- E. Relatives' positive attributions/attitudes
- F. Better familial relationships
- G. Coping with stress
- H. Self-management of symptoms
- I. Knowledge about schizophrenia
- J. Knowledge & use of services



MANCHESTER 1834 Manchester Mental Health and Social Care Trust NHS

Consensus Study: Session 2

Alternatives to 'proxy family' – choose your favourite!

1. Adopted families
2. Befriending
3. Nominated families
4. Chosen families
5. Substitute families
6. Support families
7. Alternative families
8. Surrogate families
9. Family support

MANCHESTER 1834 Manchester Mental Health and Social Care Trust NHS

Consensus Study: Session 2

Alternatives to 'psycho-education' – choose your favourite!

1. Shared learning
2. Psychological education
3. Mental health education
4. Information sharing
5. Mental (ill) health awareness
6. Psychological shared learning

MANCHESTER 1834 Manchester Mental Health and Social Care Trust NHS

Session 3: Delivery

- Adapt the *delivery* of FI to meet the particular needs of African Caribbean groups
- Agree on *key issues to support delivery* of CaFI
- To inform CaFI training manual

MANCHESTER 1834 Manchester Mental Health and Social Care Trust NHS

Session 3: Delivery

Key themes from Focus Groups:

1. Ethos: focus on 'wellness'
2. Therapist cultural awareness
3. Therapeutic relationship – power balance & building trust
4. Illness models/ spirituality & belief systems
5. Shame & stigma
6. Family dynamics & structure
7. Social networks & significant others
8. Help-seeking & care pathways
9. Importance of choice & flexibility (vs. resources)
10. Language & communication

MANCHESTER 1834 Manchester Mental Health and Social Care Trust NHS

Session 3: Delivery

Key themes from Focus Groups:

1. Ethos: focus on 'wellness'
2. Therapist cultural awareness
3. Therapeutic relationship – power balance & building trust
4. Illness models/ spirituality & belief systems
5. Shame & stigma
6. Family dynamics & structure
7. Social networks & significant others
8. Help-seeking & care pathways
9. Importance of choice & flexibility (vs. resources)
10. Language & communication

Session 3: Delivery

Therapist cultural awareness


- Understanding needs & illness within cultural, faith & spiritual context
- Avoid preconceptions and stereotypes of 'African Caribbean culture'
- Focus on individual/family values & beliefs versus 'African Caribbean culture'
- Awareness of differences
 - Ethnicity, faith, class, age, gender, education level, sexual orientation

Session 3: Delivery

Therapeutic relationship – power balance & building trust

- Ethnic matching
- Empowerment – family and service users as experts
Shared learning 'three-way process'
- Building trust for engagement
- Mutually respectful exploration of beliefs – 'illness', problems & solutions

Is there any thing else
you think we should consider?





CaFI Culturally-adapted
Family Intervention
African Caribbean service users & families

End of session 3...

Networking & refreshments in the Hub
Feedback sheets!

Thank you



Please contact us....

Amy Degnan

Research Project Manager

– 0161 275 5224 / 07847 865 835

– amy.degnan@manchester.ac.uk

Dr Dawn Edge

Principal Investigator

– 0161 275 2570

– Dawn.edge@manchester.ac.uk

