EQUALLY Connected

Equally Connected* Report 12

Community Conversation with BME Carers

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Equally Connected is an action research project using community development approaches, including the creative arts, to learn from Black and minority ethnic communities about:

- attitudes to, and experiences of, mental health
- what helps maintain well-being
- effective ways of challenging stigma and discrimination

This evidence will be used to improve understanding and help ensure that services and systems of care (such as the Integrated Care Pathway (ICP) for people with depression) are designed to meet the needs of the diverse Black and minority ethnic communities within Edinburgh and the Lothians.

Equally Connected is funded and supported by NHS Lothian and NHS Health Scotland and based at Health in Mind in Edinburgh

NHS Lothian

Health in mind

Community Conversation

1. Context

During initial scoping by Equally Connected in 2009, and at subsequent meetings, staff at the Minority Ethnic Carers of Older People Project (MECOPP) repeatedly raised their concerns about the impact caring can have on the mental health of carers, particularly those from Black and minority ethnic (BME) backgrounds. With this in mind, Equally Connected and MECOPP decided to hold a Community Conversation with a small group of South Asian carers on 7th February and a follow up session on 27th April 2011. This report details the findings from both events.

Community Conversation is a tool that was developed as part of the Mosaics of Meaning initiative in Glasgow[1]. It is a useful method which can be used with BME and refugee and asylum-seeker communities to initiate discussions about mental health and challenge the stigma that often surrounds the issue of mental health.

1.1 Preparation

To encourage participation, and to allow ample time for discussion, socialising and support, we included the Community Conversation as part of a day event for carers which had a clear focus on promoting positive mental health and wellbeing.

In advance of the meeting we spent time considering what the barriers might be which would prevent carers attending on the day. Where necessary, travel costs were offered to those who had mobility problems. We anticipated a range of ethnicities and MECOPP staff suggested it was best to conduct the session in English with interpretation support provided, if required, by a bilingual member of MECOPP staff who was well-known to participants. The personal circumstances of some carers meant they would be unable to attend for the whole day, so the day was structured to allow some to 'drop in' for just part of the event.

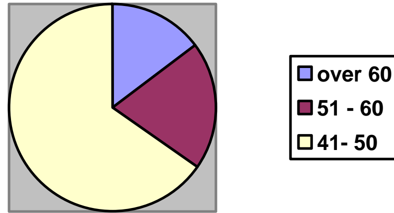
A colourful, eye-catching flyer was devised by Equally Connected and circulated to by MECOPP. The day was scheduled to run from 10.30am to 3pm, including the provision of refreshments and, at the end of the day, complementary therapies.

1.2 Monitoring Information

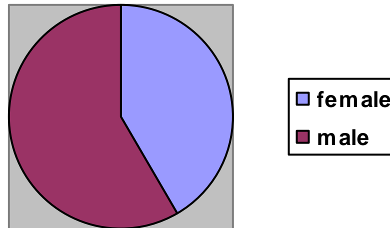
Thirteen people attended, 3 for part of the day and 10 for the full day, details were collected for 12 participants:

Age

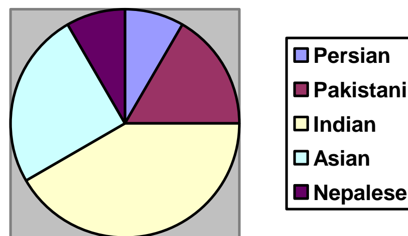
[1] Glasgow Anti Stigma Partnership (2008) Mosaics of Meaning http://www.healthscotland.com/documents/1954.aspx)



Gender:



Ethnicity:



2. Community Conversation

2.1 Ice-breaker

We began the day with an ice-breaker game which encouraged participants to mix, learn names and find out new information about each other. We used 'Human Bingo' with questions specifically chosen to reflect the likely interests and backgrounds of participants. Despite some initial hesitation participants quickly joined in and the exercise worked well to 'break the ice' and encourage participants to share information about themselves in a fun and non-threatening way.

2.2 Gathering baseline data

In an attempt to measure any change in attitude/opinion we began by asking participants to rank 7 statements according to whether they agreed or disagreed with them. We planned to repeat the same exercise at the end of the day. Despite the success of the ice-breaker, it was clear that participants were unsure about being asked to share their views on paper. There were also a few comments like *'more forms'* and, for some, an obvious reluctance to read and write in English. Nine people completed the form, one person refused.

"I would be happy for someone with a mental health problem to marry into my family"			
Strongly agree	Agree 2	Disagree 2	Strongly disagree 5

"If I had a mental health problem, I wouldn't want to tell anyone about it"			
Strongly agree 4	Agree 2	Disagree 2	Strongly disagree 1

"People with mental health problems are to blame for their own condition"			
Strongly agree	Agree 4	Disagree 4	Strongly disagree 1

"The majority of people with mental health problems recover"			
Strongly agree 1	Agree 4	Disagree 2	Strongly disagree 2

"Caring for someone can affect your mental health"			
Strongly agree 5	Agree 3	Disagree 1	Strongly disagree

"Anyone can experience a mental health problem"			
Strongly agree 1	Agree 3	Disagree 5	Strongly disagree

"I would feel unsafe around a person with mental health problems"			
Strongly agree 1	Agree 3	Disagree 5	Strongly disagree

2.3 What affects our Mental Health?

By way of introduction, we explained the session was about exploring attitudes towards, and experiences of, mental health, stressing that there are 'no experts' and we all have mental health. The key message was that our mental health is a combination of how we are feeling, our wellbeing, our happiness and our ability to cope. We can have good mental health or poorer mental health and everything in between, most of us moving along the continuum at different points in our life. The World Health Organisation definition was then shown on a flipchart:

'Mental Health is not just the absence of mental disorder. It is defined as a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to her or his community.'

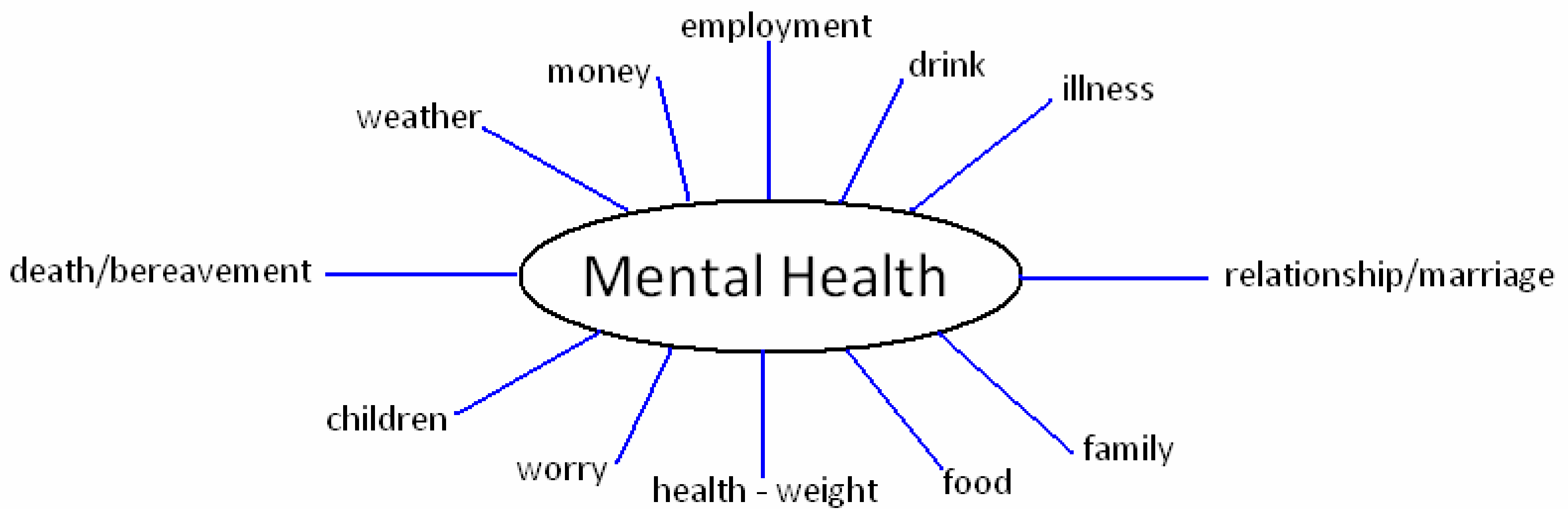
Initial comments included:

"they say mental health but really what we are talking about is depression, that is mental health, people with depression"

"there are many barriers for us Asian people"

"nobody wants to talk about these issues in our community, you'd be pushed out even more if you did talk"

The group were then asked to list all the different factors which can affect their mental health



2.4. What are Mental Health problems?

We then explained that today we would focus on the most common mental health issues: stress; anxiety and depression. For each issue, group members were asked to consider how we think, feel and behave when we experience each issue. Despite a full explanation, at times, in each case, participants did not always recognise the differences between think/feel/behave. The results are recorded below:

2.4.1. Stress

Think:

- *how to remedy/do something good*
- *laziness*
- *can't cope*
- *angry*

Feel:

- *blood pressure goes up*
- *insecure*
- *angry*
- *lonely*
- *moody*
- *you're the only one*
- *destructive/violent*
- *start breaking things*
- *don't eat/eat too much*

Behave:

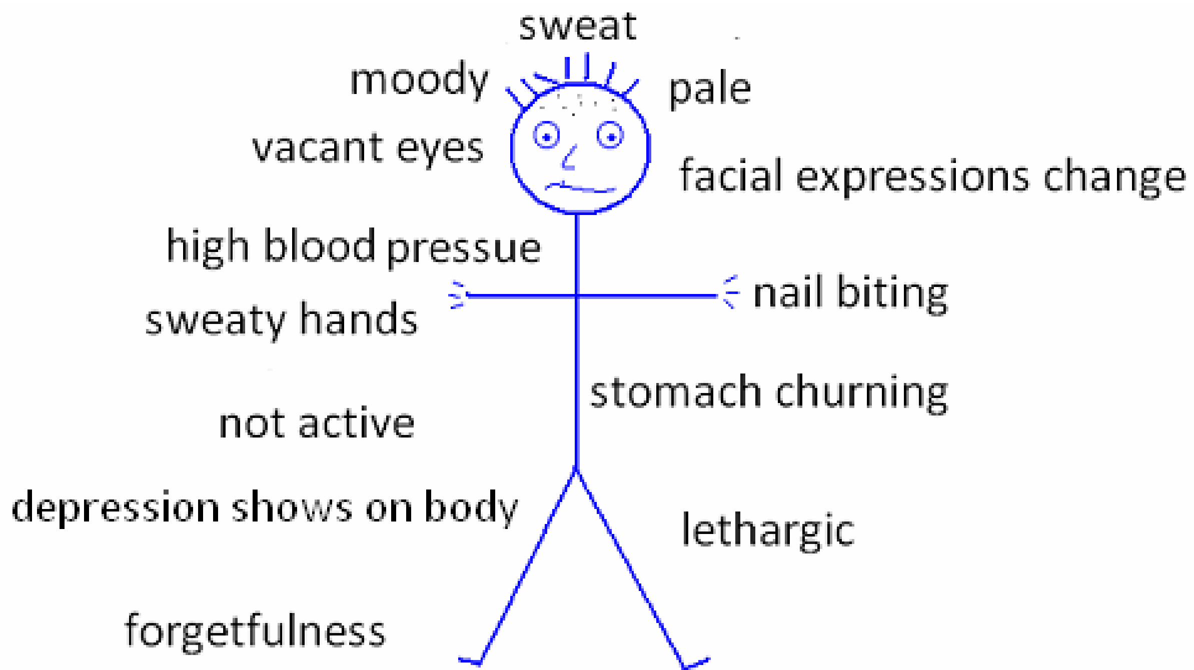
- *hide away*
- *public shame*
- *start to drink*
- *look at the TV but don't know what's on the screen*
- *quarrel with wife/husband/family*
- *not go out*
- *go into a silence/don't want to talk with others or phone someone*
- *hard to concentrate*
- *emotional – crying so much*
- *scream/cry*
- *not take the dog out*

Additional comments made during this session included;

- *'I can't even speak, I cry first'*
- *'I don't want to go out and show my face, they may know you have been crying…[I] sit in one corner and watch TV'*
- *"in our community they like to pretend it doesn't happen ….but we know it does"*
- *'You don't want to face it [because] you don't enjoy it'*

2.4.2. Anxiety

Using a 'stick figure' participants were asked to say how they think, feel and behave when experiencing anxiety



Again, specific comments included:

- *'The smile disappears'*
- *'Go for a long drive'*
- *"Again the sobbing, can't make sense or think at all straight"*
- *"feeling sick deep inside, it immobilises you"*
- *'Sometimes you wait for along time at a bus stop and the depression shows (bus may pass by but you don't notice/care)'*

2.4.3 Depression

Think:

- *strain*
- *how can I get money?*
- *money problems*
- *Will I find another job?*
- *Can't do anything about it*
- *Long-term worry*
- *Dementia*
- *All bad memories return*
- *Bring sorrow to close friends*

Comments:

- *'Strain [stress] is part of depression'*
- *'Some people have permanent depression as part of a mental health problem'*

- *'Stress is a temporary thing but is part of depressio which lasts longer, foever sometimes'*
- *[When it accumulates] 'stress can lead to depression'*
- *'You get frustrated, then depressed. You have to overcome it, but sometimes you can't"*
- *' If I lost my job, I may be depressed because I would think about money problems…'*

Feel:

- *headache*
- *isolated*
- *angry*
- *crying*
- *bang head against wall*
- *touchy*
- *sad*
- *low mood – doing nothing*
- *helpless – you had to do it*
- *guilt*
- *frustration*
- *him – careless person makes me depressed*

Comments:

- *'You are helpless when you are caring for someone'*
- *'You have no choice when you are caring for someone, you have to do it'*
- *'I feel great when I meet someone miserable because I feel great when I cry and they cry too' [sharing one's woes]*
- *'My own son doesn't care. He doesn't give me any time'*
- *"I feel alone, no one to talk too, don't want tablets, want other things but don't know, for me tablets no good but what else"*
- *'You feel loneliness'*
- *'All the bad memories, they come back to your mind'*
- *'You are always thinking of them, never yourself'*
- *'Medicine is what is keeping me depressed, having to take medicine, but no other choice"*
- *'If someone calls, my depression is gone, bad feelings are gone, I feel like taking my shoes and going out there'*

Behave:

- *need trust*
- *look at/see happy photographs of good times from the past*
- *yoga*
- *painting*
- *remember good memories*

- *keep quiet/forget yourself*
- *hot cup of tea*
- *depression comes from medicine*
- *go out – change my mind/improve my mood*
- *walking/sleeping – can have both positive and negative effect*
- *get a dog*

Comments:

- *'I am the kind of person who hides it. I put on a false good face'*
- *'Fresh air helps me'*
- *'Crying provides relief'*
- *'Bang your head against the wall, make a hot cup of tea and cry again, what can you do?"'*

During this discussion particpants asked about the difference between stress and depression? It was explained that we all experience symptoms of stress, anxiety and depression some of the time. Some stress is even considered a good thing and healthy as it helps to motivate us. But if you begin to feel stressed most, or all, of the time, then it could be having an adverse effect on your health. It is okay to feel a bit anxious before a test or interview and most people feel sad after a bereavment. However, when these thoughts, feelings and behaviours begin to affect our ability to lead our daily lives then it is a good idea to ask for support.

As the group started to share their own experiences they also began to help each other and share tips on dealing with stress, anxiety and depression. The quotes reveal There was also a strong sense of fatalism in the discussions, a sense that '*you don't get better'* and limited awareness of non-pharmacuetical therapies or options for dealing with depression or stress.

2.5 Impact of caring

Participants were then asked to specifially think about the impact of caring on their own mental health:

- caring brings depression
- frustration, nothing I can do so learn to live with it
- no time for yourself, relax yourself
- being isolated
- always thinking how you can make them happy
- loneliness
- have to learn to overcare
- better to come out

Comments:

- *"In Asian culture, they just think it is growing old, there really is a need for public education in our communities"*
- *"Most of the time I just feel very lonely, my family are around but it is me that is there all the time. Even when I am not I am still caring. Nobody in the community wants to know you, they slowly start to stay away. When we do go out they shun us and it is as if I am a nobody too, they don't see the person any more"*
- *"I didn't know what to expect today, I must admit I didn't think it was for me but it was good to talk"*
- *"I look after my mother, in my opinion she takes too many tablets, the Dr doesn't really listen to her or offer other treatments, just seeing her as an old Asian lady who doesn't speak English good. But I can see how low she is and how much she has gradually just cut herself off, she neds to get out and be with others in her age group, but in our culture you tend to keep such problems hidden, peeople act like it is a disease you can catch. I know it is awaful but feel what can I do?"*

One person who cares for a family member with mental health difficulties added: *"my careless X, causes my problems, no support and shame for my people, I know they judge me and blame me. I know X has an illness but they don't see that, only blame me as the carer…it is all in my head, my headaches, my shame. I tell X makes me headache and tense and then I have to tell X to leave, but I feel the shame, the guilt for me like it is my fault".*

During this session one member of the group became visibly upset and left, with support, to compose herself in a seprate room. When she left other group members immediately commented: *"that's what it's like, it is better to get it out", "too often you just keep it inside and hidden, it is not good for you", "we need to talk about these issues but where, nobody wants to know".*

2.6 Recovery

Due to the group size and the fact they were 'gelling' well as a group, this part of the Community Conversation was carried out without splitting the group despite the suggestion in the Community Conversation manual of splitting the group into two. It was immediately clear that the concept of recovery is something the participants had little grasp of. There was very limited awareness or understanding of 'recovery', particularly with regard to mental health.

In addition, the facilitator sensed some fatigue in the group by this point and that may have contributed to the lack of participation. At this point the facilitator tried to bring the onus back onto the participants by expressing what had already been said at the start of the conversation: that no one in the room is an expert and we all learn from each others' views and experiences. There was agreement with this idea, however, it was apparent that more would be required to raise awareness and

understanding of the concept of recovery and particularly how certain methods can be applied to deal better with mental ill-health and stress.

2.7 Stigma

In this section the aim was to discuss issues such as 'as we all have mental health and mental health problems affect us all, why don't we talk about it openly, why do we keep it hidden?', 'What stops us?', responses are recorded below:

- culture/way we've been brought up

- marriage – own communities small/everyone knows

- we hide because it may have consequences for family/status marriage

- we want to safeguard our families

- sensitive issues i.e. gossiping (but it hurts us), family, financial (supposed to keep quiet about these)

- nobody can help (they can make it worse)

- easier to hide

- mental health can be passed on through families

- not easy e.g. if they find out your sister has mental health problem they think it can be can be passed on

Again, a certain sense of fatalism was observed in that *'there was nothing you could do"* or "*difficult to know how because there's no cure for certain things".*

Posters from the 'see me' campaign were displayed to encourage discussion about challenging stigma and assessing if participants identifed with the poster messages or not. Only two suggestions were made and many commented that the 'see me' posters were *'not relevant', 'not appropriate' for my culturee "still a long way to go", " talk more openly because this culture is different (not as stigmatised as ours)".* There was insufficient time to explore these issues further and a future session is suggested, perhaps in collaboration with 'see me'.

Similarly, attempts to ask participants to complete the statements mentioned in section 2.2 again failed as most said they had already done them.

3. Lunch and Complementary Therapies

As well as enjoying a good lunch, there was a lot of informal discussion on a one-to-one, or small group, basis about the issues raised during the morning session. Facilitators were all surprised at how open participants were and how quickly trust had been built up to encourage people to share their experiences of dealing with or coping with mental health issues. Such discussions also provided an informal opportunity to pass on information about local support services such as 'befriending', Saheliya and Men in Mind. It was clear there was a lack of awareness about the range of initiatives available to help tackle stress and depression as one person said *"I just thought it was tablets, that's all I have ever heard about and*

that's why I wouldn't go to the GP. I have seen what tablets do to others. I didn't know about any of these things you are mentioning".

With our aim of promoting health and well-being, after lunch, participants were offered the opportunity to try massage or reflexology using a male and female therapist. These short taster sessions were very popular, comments included:
"I'd often wondered what that was about but had never tried it, can't believe how relaxing it was in such a short time"
"never had foot massage before, he was very good, I would go for more of that"
" I have tried reflexology before so I know the benefits but today was great because my (family member) tried it, probably because it was just a wee shot, but X now knows it can relax you and X needs to know ways to relax for their mental health"
"I feel more relax now, I feel better to stand and give support, before I just had the bad headache all the time"

4. Evaluation
At the end of the day participants were asked to comment on the whole event by placing sticky dots on an evaluation poster. The poster was deliberately colourful and easy to use, thereby enabling those with limited English to participate. In addition, being cognisant of earlier comments about 'forms', it was important the evaluation was not viewed as *'another form'* but at the same time captured some feedback on the day.

Tell us what you think!
Q. How was the .....

How was the...	Good	Okay	Not Good
Complementary therapy	x 9	x 1	
Venue	x 8	x 1	
Community Conversation	x 10	x 1	
Food	x 8		

4. Next steps
As discussed earlier there was little awareness or understanding of the concept of 'recovery' and only limited time to explore stigma, in particular ways to challenge stigma. A future session was recommended with a focus on these specific issues.

5. Follow Up
On 27th April, a follow up session was held with BME carers in conjunction with MECOPP and 'see me'. The focus on recovery was an attempt to tackle the fatalistic attitudes previously expressed by some of the carers about their situations. We

worked closely with 'see me' to plan the event and a similar promotional poster was designed by Equally Connected and distributed by MECOPP.

Thirteen people attended the follow up session (ten men and three women) and eleven identified as being carers. The majority were over 60 and two people said they were aged 51 – 60.

5.1 Structure of follow up event

Using a similar format to the February event, the programme had a mixture of activities to encourage discussion about mental health, as well as lunch and complementary therapy tasters. We began with a short summary of the previous event as several participants had not been present at the earlier event and then moved on to present some statistics relating to mental health and wellbeing to give the participants a clearer idea of some of the facts and to help dispel some myths.

5.1.1 Derogatory Word Exercise

On post-its, participants were given a minute to write down derogatory words they could think of for people with mental health difficulties. The exercise was designed to be non-threatening to allow participants to share without fear of judgement by others. The words could be any language and 3 or 4 languages, including English, were used. Each participant produced at least 1 word with many of them producing 2 or 3 derogatory words each. The words were then shared on the flip chart.
The second part of the exercise asked people to repeat the process but for people with a physical medical condition, in this case, diabetes. As expected, there were no words produced for the second part of the exercise. We used the outcome of this exercise to highlight what we mean by stigma surrounding mental health. We briefly discussed the sheer amount of stigma there is in smaller communities as well as the wider society, including in the media. See me then gave an overview of the different strategies and processes they have used in their campaign to tackle stigma surrounding mental health, such as writing competitions, photography competitions and posters. Several participants reacted negatively to the 'labels' posters feeling that could make people feel worse. Others commented that the posters would be meaningless in their culture. Although we had planned to engage participants in designing their own poster, there was insufficient time on the day to do this.

5.1.2 The four quadrants of Mental Health and Wellbeing

This exercise approached the issues surrounding recovery using a hypothetical person who was a carer – Mr. Ahmed – who had difficult circumstances in his life. Some of his circumstances were that his wife had cancer, he was not socially active anymore, he felt as though he had no time for himself, he didn't express his worries to anyone and he felt depressed. Group members were asked how Mr Ahmed could be supported to recover from this situation and ways he might be able cope better. We drew a diagram of the four different quadrants a person can be placed in. We highlighted that neither mental health nor wellbeing is static through life, and many

events, small and large, can trigger them to move in either a positive or negative direction. We discussed how it's possible to have a condition like depression and still lead a reasonably productive life and have good wellbeing.

During this exercise, one participant became visibly upset as he shared his own experience as a carer for his wife: *"I am one of those unhappy people, get up 7 every morning, get prayer, then read book, 7-9 (14 hours) everyday all the same…how many hours I am alone, she's mentally too much trouble, everything I do is wrong (to her)".* These comments evoked much sympathy from the others. In relation to caring, one person said *"sometimes you can't deal with it anymore*". The carers' frustrations and feelings of helplessness also showed in comments such as *"only way for him to feel better is if wife feels better; family in our community is important, always has been, always will be for us".*

5.1.3 See me story

During this part, we shared the story of a carer looking after a disabled child, the winning entry in a creative writing competition. The author wrote that many people were always empathetic towards her daughter, commenting on how well she was doing, but on one occasion someone had asked how the mother was coping. The mother was moved by this as no-one had previously asked about how she was feeling before. The story highlighted how carers are often overlooked and the immense stress that's constantly placed upon them often goes unnoticed by others.

5.1.4 Own experiences

This exercise asked participants to share a difficult experience from their past with the person next to them and come up with one word that helped them get through the difficulties. This exercise was also designed to be non-threatening as it was only the words which were shared with the whole group, and not the details of the individual experiences. The words were recorded on a flip chart for the group to hear each other's inspirations. Popular words that came up were *'friends'* , *'freedom'* and *'husband/wife'*. Two participants said *'praying'* had helped them overcome their problems.

5.1.5 Comments and evaluation

Informal evaluation was carried out by asking participants to write their feedback on post its. Comments included: "*good discussion"; "been lovely having people around us*"; and that they enjoyed the *"massage and talk*"; "*You learn by sharing experiences*". Some other constructive remarks were: "*need to make people more open and comfortable"; "own language better understand"; "It can't just be a one-off".*

Throughout the session, there were a couple of participants who were quite vocal in their criticism of strategies such as the poster campaigns. In particular they argued that some ideas which work with the wider population will not have success

amongst BME populations. There was much sentiment that BME communities (carers and otherwise) need other BME workers or those who understand the different cultural factors to engage with them. Language barriers were also cited by participants as being a key factor in lack of engagement of BME people with different services and isolation within communities.

6 Conclusion and next steps

In general, the two sessions were visibly appreciated by the participants. However, there was still room for improvement as some tasks generated more participation than others. It was clear that participants felt there needs to be a regular drop-in style facility, or outdoors activity programme, for BME carers. Participants wanted to see regular sessions like this where carers could meet others, learn from each other, as well as socialise.

It is unfortunate that there was insufficient time to carry out the poster task and this is an area which could perhaps be followed up by MECOPP and 'see me'. It could be very useful as it would give a valuable insight into the mindsets of carers themselves and how they view things like anti-stigma campaigns. Future work could also focus on encouraging participants to voice their opinions by using the arts, tasks like designing posters with captions or make greater use of photography or film to capture the views of carers.

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