‘Wise up to cancer’; adapting a community based health intervention to increase UK South Asian women’s uptake of cancer screening

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Conflict of interest

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Data Availability Statement

- Data openly available in a public repository that does not issue DOIs

ABSTRACT

UK South Asian women are less likely to engage with cancer screening than the general population and present later with more advanced disease. Tailored interventions are needed to address barriers to these women accessing screening services. ‘Wise up to cancer’ is a community-based health intervention designed to increase cancer screening uptake. It has been implemented within the general population and a study was undertaken to implement it within a South Asian female community. This paper explores one workstream of the wider ‘Wise up to Cancer’ study which involved working out how best to adapt the baseline questionnaire (the first part of the intervention) for South Asian women in an inner-city location in Northern England. The aim of this workstream was to evaluate what worked well when implementing the adapted ‘Wise up to Cancer’ with South Asian women.

In 2018, we conducted qualitative semi-structured interviews and focus group with 14 key stakeholders; women who had received the intervention, health champions and community workers to explore their perspectives on how the adapted intervention worked within a South Asian female community. The interviews were audio recorded or (notes taken), data were transcribed verbatim, and the dataset thematically analysed. We found that training peers as community health champions to deliver the intervention to address language and cultural barriers increased participant engagement, was beneficial for the peers and supported participants who revealed difficult social issues they may not have otherwise discussed. Accessing women in established community groups, following planned activities such as English language classes worked but flexibility was needed to meet individual women's needs. Further research is needed to explore the impact of adapting 'Wise up to Cancer' for this community in terms of engaging with cancer screening.

Key words: South Asian women, cancer screening, community health champions, peer support, adapting a health intervention, community groups, faith-based organisations.

What is known about this topic

- How health interventions have been previously adapted to use with BAME communities
- Peer led interventions can help address language and cultural barriers to BAME women engaging with cancer screening services.
- Delivering cancer screening interventions with BAME women in small group community settings increases screening uptake.

What this paper adds

- How to adapt an intervention about healthy lifestyle and cancer screening to use with South Asian women

- Engaging peers to deliver an intervention with South Asian women may support them to reveal additional important personal issues that may otherwise not be revealed.
- Delivering the intervention in established small community groups following an unconnected planned activity increased South Asian women's receptiveness to receive the intervention.

INTRODUCTION

UK South Asian women are less likely to attend breast and cervical screening than other populations and are more likely to present for health care when cancer is advanced (Anderson de Cuevas et al., 2018; Forbes et al., 2011; Marlow, Waller, & Wardle, 2015). The UK has an agenda to diagnose cancer earlier in the general population (Department of Health, 2013; NHS England, 2014) and with Pakistan, India and Bangladesh South Asian being the largest Black Asian and Minority Ethnic (BAME) group (Office for National Statistics, 2011), it is vital that community based health interventions are developed to increase cancer screening and therefore early detection of cancer in these women. This will increase the likelihood that cancer is successfully treated, ultimately save women's lives within South Asian communities.

Research has identified that there are individual and structural factors which create barriers to South Asian women accessing cancer screening services (Anderson de Cuevas et al., 2018; Crawford, Ahmad, Beaton, & Bierman, 2016). They may lack knowledge about cancer, the importance of screening for early diagnosis and how to access it. This lack of knowledge can be exacerbated by language barriers. The subject of cancer may be stigmatised by the local community, which can deter women from attending screening. There can be barriers due to expectations on gender roles within families and women being required to seek male guidance prior to accessing health care. Women may be embarrassed to attend, or they may fear that a male professional will undertake the screening. When developing a community

health intervention targeting South Asian women, it is important to consider how these barriers can be addressed within the community to facilitate women to engage with cancer screening.

'Wise up to Cancer' is an existing health intervention comprising of a baseline questionnaire and follow up telephone interview. The baseline questionnaire is delivered in a community setting by a peer who is a trained community health champion. The aim of the questionnaire is to facilitate a conversation to increase the recipient's awareness of what constitutes a healthy lifestyle to reduce cancer risk, the signs and symptoms of cancer and the importance of screening to detect the condition early and increase survival rates. The outcome of the conversation is the recipient setting goals to improve their lifestyle and engage with cancer screening appointemnts. The 'Wise up to Cancer' intervention has been previously delivered within the general population in Northern England by opportunistically approaching people in the local area (Woodward, Seims, White, Bunyan, & O'Dwyer, 2018). We secured funding to undertake a study delivering 'Wise up to cancer' with South Asian women. It is important to adapt health interventions to increase their relevance when used with BAME communities (Barrera, Castro, & Holleran Steiker, 2011; Jepson, Harris , Platt, & Tannahill, 2010; Teuscher et al., 2015) and this paper reports on how we adapted and the evaluated 'Wise up to Cancer' with a community of South Asian women in an inner city location in Northern England.

There is a wealth of evidence evaluating how successful health interventions have been adapted for use within BAME communities, resulting in the development of conceptual frameworks to guide the adaptation process, for Netto, Bhopal, Lederle, Khatoon, and Jackson (2010) who developed a five principle approach to adapting a healthy lifestyle intervention for a BAME community and Davidson et al. (2013) who developed a 46 item tool kit and decision tool to guide adapting behaviour change interventions. Our literature review found no research relating to adapting health interventions for South Asian women in the

context of cancer screening. This paper reports on the workstream from a larger study to address the research to evaluate what worked well when implementing the adapted 'Wise up to Cancer' with South Asian women,

METHODOLOGY

Intervention development

The 'Wise up to Cancer' study received ethical approval from the NHS Research Ethics Committee reference 235627. A service user group of women who represented the target population was identified through our community networks. This group was established to review the way that the previous 'Wise up to Cancer' intervention had been delivered and how it could be adapted for this context to ensure the key messages reflected the target groups social and cultural norms (Davidson et al., 2013) and would therefore be considered acceptable and relevant. This included a discussion of barriers South Asian women may face accessing cancer screening and how the intervention could be adapted to optimise uptake. The content and wording of the baseline questionnaire was edited, for example South Asian women face structural barriers accessing standard health promotion advice including culturally appropriate advice about diet in the correct language (Cross-Bardell L, 2015) and the baseline questionnaire was adjusted to address this. The service user groups also decided that it would be appropriate to deliver the intervention within established community groups as well as opportunistic one-to-one delivery, which was the approach in the first 'Wise up to Cancer' study (Woodward et al., 2018).

The service user group discussed the criteria for selecting people as community health champions. The decision was to select women who were peers to help address possible language and cultural barriers. Volunteers for this role were approached by advertising the post through established community groups and word of mouth. In this context we considered that women we were aiming the intervention at would be different ages, may speak different languages, have varying levels of health literacy and would be from different

cultural and religious background, factors we needed to be mindful of when recruiting and training community health champions (Netto et al., 2010). The volunteers received a training session around a healthy lifestyle, cancer and screening, role boundaries, data protection and confidentiality, safeguarding and lone working as well as being provided the opportunity to practice completing the baseline questionnaire.

Intervention delivery

South Asian women were approached through established community groups which they attended and for the one-to-one opportunistic delivery, in the local area including outside shops and the park. Key gatekeepers within the community groups were approached to facilitate access to the women (Netto et al., 2010) and to 'endorse' the 'Wise up to Cancer' project within the community (Davidson et al., 2013). A total of 355 women whose families originated from Pakistan, India, Bangladesh or Nepal received the baseline questionnaire from the 'Wise up to Cancer' intervention. The women were aged between 24-75 (the target age to cover the three screening types offered- cervical, breast and bowel). The baseline questionnaire was delivered in the woman's preferred language by one of the trained community health champions (n=25).

Intervention evaluation

To achieve the workstream aim a qualitative approach was undertaken, conducting semi-structured and focus group interviews to explore perceptions of key stakeholders about the intervention.

Participants and data collection

Community health champions (n=5) who had delivered the intervention, community workers from with the accessed organisations (n=4) and women who received the intervention (n=5) were identified and accessed through community organisations where 'Wise up to Cancer' was delivered. After gaining informed consent, the community health champions, and community workers were interviewed using a semi-structured approach. Women who

received the intervention attended a focus group. All the women spoke English and the interviews were either audio recorded, or handwritten notes were taken, when consent was declined for audio recording.

Method of analysis

Recorded interviews were transcribed verbatim and handwritten notes added to the dataset. Data were analysed thematically using the principles of Braun and Clarke (2006). This involved two members of the team independently coding the data, grouping codes together to create categories which were then merged into the final themes. The themes were agreed through consensus.

FINDINGS

Four key themes emerged from the data which evaluate the implementation of the adapted intervention in the real-world setting with South Asian women. These are discussed below:

THEME ONE: ENSURING CULTURAL SENSITIVITY

The community health champions discussed the relevance of the baseline questionnaire when they were delivering it to South Asian women. This included the way that the questions about healthy lifestyle were worded. Questions about physical activity were highlighted and the importance of wording the question in a way that is culturally sensitive. For example, when suggesting types of physical activity South Asian women could engage with, the community health champions stressed physical activities that could be performed in traditional dress were important. Also, the need for activities where women would not be mixing with men such as women's only exercise classes. The community health champions also talked about the need to ensure suggestions to increase physical activity levels were age relevant and were realistic when considering women's role within the family:

'The women don't have transport to go to the gym, if they are middle age they can go to the gym or community centre. Those that couldn't go to the gym can go to the park or walk, they can do housework' (community health champion 1)

Discussing healthy eating was another example given by the community health champions. They stressed the importance of applying the different food groups to the context of a South Asian meal. They also discussed the need to be culturally sensitive to the difference between daily food and hospitality food. Daily food could be healthy, but there may be an expectation that hospitality food is prepared in a certain way which includes unhealthy ingredients:

*"..the women would laugh and say we prepare our food at home and keep it healthy but when we come out, it can be deep fried and full of sugar, we have Asian snacks, sweets and cakes….Wedding food was another example cited by women as being unhealthy, but tasty nonetheless". (*community health champion 3*)*

THEME 2: THE COMMUNITY HEALTH CHAMPION AS A PEER

The community health champions discussed how their being peers was beneficial to engaging women with the baseline questionnaire. They believed being from the same background (Indian and Pakistani) helped them to build a rapport with other women of the same background more readily. They also believed that being peers led to trust and reported that some women had revealed personal issues such as domestic abuse, destitution and poor mental health that they could discuss and then signpost the women to appropriate services.

'…she felt comfortable in disclosing that and thought that information was confidential, it wasn't going to kind of go elsewhere unless needed…Whereas I think if that was somebody

with a different ethnicity she probably wouldn't have felt that way.' (community health champion 2).

Also, building trust was believed to influence women asking for help with more general issues:

'There was one lady in one session who wanted more assistance with her age and her pension issues….she said that her age on her passport was incorrect and because of that she was having to work, which meant that she couldn't apply for pension earlier' (community health champion 3)

Despite being a peer, the community health champions believed that it took time and repeated contact with women to build a trusting relationship which enabled them to deliver the intervention. They believed it was desirable to attend community groups to meet the women on a few occasions prior to presenting the intervention to them:

'…just sort of visiting them a few times and get kind of recognised with them, as opposed to just going in and saying 'this is what I'm doing', just build that rapport with them initially and then go back in like let's say the third or fourth time' (community health champion 3)

As well as helping to build a relationship with the woman, the peer found that speaking the same language as the women helped her to be involved when she may otherwise have been excluded from the project:

'Because our language is same and I know the other few languages, Punjabi, Pashto a little bit, and I just, Arabic as well, so it was easier and they were comfortable as well' (community health champion 5).

As well as the benefits of being a peer to the women receiving the intervention, the community health champions also benefited from the experience. They reported that learning about a healthy lifestyle and cancer screening had a positive impact on their own health and wellbeing. They also discussed how their self-confidence increased through working as a community health champion:

*'I think I learnt as well how important this is: a better lifestyle, eating habits, walking, exercise and I have more confidence in talking to people and new people, so it's new things for me....I got confident to speaking with person you totally don't know…' (*community health Champion 4*)*

THEME 3: A FAMILIAR ENVIRONMENT

The community health champions found that accessing women through local community groups was a successful strategy. They were well established within the local community centres and were convenient for the women to attend; were within walking distance of women's homes, were timed around lunchtime prayers and taking children to and from school and some groups had existing interpreters and creches. In addition, women had an existing relationship with the community centres which community workers believed encouraged them to engage with the intervention:

'I felt because the centre was quite trusted in by the community around the centre, so having the project here was beneficial, first we didn't have to go and tell them about the project, and build that trust up, the trust was already built…so they found it easier to talk…' (community centre manager 2)

Community health champions also accessed women through local schools who ran community engagement programmes. A school worker believed this was successful at engaging women with the intervention because they were familiar with this environment:

'The school is a safe and comfortable place where the parents can come and discuss anything, no one knows why they are coming to school and they also can meet other parents…..They are a close knit group and support one another, they also learn from each other'. (school worker)

Women were also accessed through local faith organisations but this was more problematic than other community venues. They found that most Mosques and Madrassas required appropriate introductions to the community faith leaders who influence the provision of organised activities and give permission to women to participate. Connecting with a Sikh temple had similar difficulties, taking several visits to connect with the Management Committee to gain approval to attend the temple and access attendees at the optimum time on Sundays. However, once a relationship had been established, the community health champions reported facilitating successful engagement on several occasions at the temple.

Women were also approached opportunistically on a one-to-one basis in public places including parks in the summer months and outside shops. However, this was not a successful strategy with the women not wanting to pause their activities to talk to the community health champions:

'They do have a certain time to run and go home. Everyone we asked made an excuse…They don't want to talk, they come to the park to run, they don't want to waste their time, they just want to run in the park and then go' (community health champion 1)

THEME FOUR: FLEXIBLE DELIVERY

The community health champions planned to deliver the baseline questionnaire on a one-to-one basis within the community-based organisations. In some contexts, this was advantageous:

> *'One to one conversations were best because it allowed our members to speak in confidence and raise any concerns they had about themselves'* (Faith organisation worker)

However, in other contexts, one-to-one delivery was not as successful. The women preferred to receive the intervention in a group context, completing the questionnaires individually but sat within the group whilst they did this:

'We would not have gone to one-to-one sessions, this (group sessions) was much better.' (participant)

Community workers believed a flexible approach to delivering the intervention was needed to engage more women. This included offering the intervention either one-to-one or within a group context:

'…the groups give them an opportunity to sort of talk and share things, but I think the one-to-ones are always useful because it gives that opportunity to people who might find it a difficult subject…' (community manager 3)

Delivering the intervention in a group was beneficial for women who did not fit the study criteria and were therefore excluded from completing the baseline questionnaire. However, they benefited from the conversations about healthy lifestyle and cancer screening which would not have happened on a one-to-one basis:

'…the age limit I think was 70, and one of our, one or two of ours are over 70 so they felt like they were being excluded, whereas at least they'd been part of that group, so they weren't completely... excluded because of their age.' (community manager 3)

The community health champions reported that the timing of delivery was an important factor influencing how the intervention worked. Delivering the intervention within community groups following an unconnected planned activity, for example English language classes or arts and crafts worked well. At this time, the group appeared receptive to a conversation about healthy lifestyle and cancer screening. However, different groups wanted different levels of engagement; some women only wanting to talk about healthy lifestyle and cancer, not engaging with the questionnaire. Other groups completed some questions but not others and some groups completed the full baseline questionnaire. The community health champions developed a flexible approach to completing the questionnaire ensure women were not deterred from engaging.

As part of delivering the intervention, community health champions found that some groups requested a visit from an expert to provide follow-up discussion specifically around managing mental health and also explaining in more detail about breast cancer and breast screening procedure. We liaised with partner agencies including breast screening services, and health professionals attended the groups and reinforced the key health messages using leaflets and props such as knitted and silicon breasts:

'…I didn't know you could get a lump under your nipple…told us all about that and she used lots of things to show us, fake boobs and that was really good.' (participant)

The women in one group identified that a barrier to them accessing cancer screening was the fear of the screening being undertaken by a stranger. They felt this barrier was overcome by inviting the relevant health professionals into the group context where they felt safe, to discuss cancer screening in an informal way:

'She showed us and explained everything that was really good because we know exactly what to expect.' (participant)

The community health champions found that to engage women in the group who were considered prominent in the community first worked well. This encouraged other women to participate, increasing the uptake of the intervention:

'Sometimes women are well known in the community, as teachers or sell something, somehow they know all the ladies, the ladies know...she says, ok we'll do this. Then we talked to that lady and then they said yes, that's fine, we want to do it as well, one by one' (Community health champion 5)

In addition, the community health champions found that in a group setting, many younger, UK born, women would engage with the intervention more readily than other older women born outside of the UK. Their presence was found to be helpful by encouraging the older women to participate in the intervention:

' The middle aged group started asking questions but…the elderly people just join in'…' (Community Health Champion 1)

The community health champions found that using simple easy to read leaflets with pictures supported their delivery of the intervention within groups. The pictures within these leaflets helped women with low health literacy but also facilitated them to feel comfortable using words in conversations which were culturally not permitted in everyday language (for example, vagina and bowels).

'*…bit of shyness because it's about their personal life...you can't use the words on a daily basis...they are familiar (the words) but you can't use them'* (community health champion 4)

DISCUSSION

The aim of this workstream was to evaluate what worked well when implementing the adapted 'Wise up to Cancer' with South Asian women. We identified four themes which related to different aspects of the implementation process. To work well, the questions in the baseline questionnaire needed to be framed in a way to ensure cultural sensitivity, the community health champions being a peer helped to overcome language and cultural barriers but also building a trusting relationship with the participant. Delivering the intervention in a familiar community environment where women had an existing relationship with other women and workers was more successful at engaging women than disrupting another aspect of their life such as taking exercise in the park. Flexibility in delivering the intervention was essential including timing of delivery, using additional resources and respecting the different levels of engagement requested by different groups of women.

Our findings suggest that training peers with the same language and ethnic background as the target women is beneficial in delivering health interventions. This supports the wealth of literature which discusses how matching peers with the intervention recipient by gender, language and ethnicity can reduce language and cultural barriers to accessing cancer screening for BAME women (Agide FD, Sadeghi R, Garmaroudi G, & Tigabu BM, 2018; Donnelly TT & Hwang J, 2015; Escribà-Agüir V, Rodríguez-Gómez M, & Ruiz-Pérez I, 2016; Hou SI, Sealy DA, & Kabiru CW, 2011). However, the wider literature around peer led interventions cautions the sufficiency of matching peers purely on perceived similarities (Liu et al., 2015; Simoni, Franks, Lehavot, & Yard, 2011). The building of a trusting relationship is considered key to successful peer intervention delivery and it is argued that this can be better facilitated through the peer having had the same lived experience as the recipient to support a more authentic relationship (Mead S, 2006; Simoni et al., 2011). In addition, Simoni et al. (2011) argue that if the peer is considered credible and similar to the recipient, this can equalise the power dynamics in the relationship, increasing engagement with the intervention. This credibility and similarity could be promoted by a shared lived experience but also a shared cultural background. It was beyond the scope of our study to identify the

Community Health Champions status in relation to cancer screening uptake, however, it is possible that because they were women of a similar age, who may have engaged with their own screening invitations, this could have normalised the lived experience (Simoni et al., 2011) and encouraged the target women to engage with cancer screening. In addition, it would appear a trusting relationship was developed with some women revealing important personal issues such as domestic abuse, destitution and poor mental health that may otherwise not have been revealed.

Delivering the intervention to groups of women in community settings, worked well in our study reflecting previous research (Escribà-Agüir V et al., 2016; Green, Tones, Cross, & Woodall, 2015; Lu M et al., 2012). We focused on accessing women through well-established local community, schools and religious settings where the women regularly attended. However, contrary to other studies, most women did not want one-to-one delivery of the intervention, preferring to be in groups with women with whom they had an existing relationship. An evidence review (National Voices, 2015) found the most successful peer support interventions to improve health outcomes was delivery either one-to-one or in larger group settings. We could find no previous research where interventions were implemented within established small groups of women with an existing relationship with each other and the community surroundings. These surrounding were described as 'comfortable', 'safe' and 'trusted' by the community workers and it would appear in the context of South Asian women and cancer screening that creating a conducive environment is as important as building a trusting relationship with the peer for successful intervention delivery.

Evidence suggests that delivering peer support interventions in a community setting using a structured activity such as exercise or book clubs improves health outcomes (National Voices, 2015). However, we could find no literature related to delivering a intervention after a previously planned structured activity not related to the intervention, which was found to

work well for the ‘Wise up to Cancer’ intervention. Women appeared receptive to a group discussion at this point, perhaps because they felt ‘comfortable’ and ‘safe’ in their surroundings. However, due to the length of the project and the delays in retrieving cancer screening data, we have no evidence that this method of delivery increases subsequent screening uptake in these women.

We experienced some difficulties connecting with faith-based community organisations for intervention delivery. Reflecting King et al. (2017) work, we found that Mosques which act as community hubs were more likely to facilitate the delivery of a health intervention than smaller Mosques without the wider community connections. However, we found most Mosques, Madrassas and a Sikh temple required appropriate introductions to the community faith leaders who influence the provision of organised activities and gave permission to women to participate. Developing a trusting relationship with faith leaders is essential due to the trust placed in them by the local population and the need for an intervention to be faith and culturally appropriate (Rai K, Dogra S, Barber S, Adab P, & Summerbell C, 2019).

There is increasing evidence of the potential of faith-based organisations to deliver health interventions, reaching people who are not reached through traditional health service routes (Aborigo R, Reidpath D, AR, & Allotey P, 2018; Hunneybell J, Khan I, & Winter N, 2019); King et al. (2017); (Rai K et al., 2019; Shirazi M, Shirazi A, & Bloom J, 2015). However, there is not yet published literature evaluating the impact of this approach on health outcomes. A recent study with stakeholders (Dogra SA, 2021) found Mosques and Madrassas were considered acceptable places for an obesity reduction intervention, however, a lack of funding and staff time were real barriers. More work is needed around addressing such barriers to optimise the potential for delivery of health interventions within faith-based settings.

This workstream formed part of a larger ‘Wise up to Cancer’ study which will be reported elsewhere. The study is limited in that we delivered a pre-developed intervention at an individual level, when structural barriers exist influencing access to cancer screening in BAME women (Anderson de Cuevas et al., 2018). Gale NK (2018) argues that the use of peer support to deliver health interventions at an individual level can lead to a ‘downstream’ problem as it does not impact on the structural barriers leading to health inequalities. Public health practitioners need to be aware of the limitations of individual level interventions and further work is needed to address structural barriers, possibly intervening at a service delivery level.

The limitations of this workstream are the potential selection bias and small dataset which comes from working with a small, local community sample of self-selecting women, community health champions and community workers. Despite this, our findings provide an insight into optimising an intervention for South Asian women. The way that we adapted the intervention appeared to help address some of the barriers to cancer screening by increasing knowledge about the importance of screening. However, this is self-reported data and due to the short duration of the project and time lag in cancer screening data, we were unable to assess the impact of this study on cancer screening uptake. Further research is needed to determine whether the intervention had an impact on engagement with cancer screening and subsequently on women’s health outcomes. Given that South Asian communities are the largest BAME group in the UK, our findings could be a good starting point for public health practitioners to consider how to adapt a complex intervention for similar health interventions in other communities in the UK and beyond.

CONCLUSIONS

‘Wise up to cancer’ is a community based health intervention that was originally developed to target the general population to increase knowledge about a healthy lifestyle and encourage uptake of cancer screening. We adapted the intervention to target South Asian

women and like other studies found that trained peers delivering the intervention with a shared ethnic and language background benefitted women in terms of trust and revealing personal difficulties that may otherwise have not been.

Delivering the intervention within established groups in community and schools settings following structured group activities appeared to work well at engaging women. The value of faith-based organisations for health interventions is increasingly popular within the literature but more work is needed to optimise such environments. We found that engaging women perceived as prominent in the community was a way to engage other women. This finding could be useful within faith-based organisations where engaging religious leaders with a health intervention could encourage the attendees to participate.

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