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Evaluation of a carers' information programme culturally adapted for South Asian families

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Authors	Parveen, Sahdia;Blakey, Heather;Oyebode, Jan
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Abstract

Objectives: The Alzheimer's Society has culturally adapted an Information Programme for South Asian families (IPSAF) who support an individual living with dementia. The objectives of this evaluation were to establish whether IPSAF had an immediate and medium term impact on those who attended and how it impacted on the wider family and the person with dementia.

Methods: An inclusive, pluralistic approach was adopted. Seven focus groups were conducted with 42 participants, and 37 participated in a pre-post knowledge quiz. Seven family interviews were conducted with 17 participants and three families were followed up after six months. Thematic analysis was conducted on the data

Findings: IPSAF was found to improve participants' knowledge of dementia leading to increased understanding of the person with dementia. Participants became more aware of available services and accessed services to make use of practical support. IPSAF was reported to have an impact for people living with dementia, with carers' newfound understanding resulting in some changes in care practice that promoted empowerment and independence for people living with dementia. There was also some evidence to suggest that IPSAF had an impact on the wider family, with participants sharing information about dementia with family members who had not attended the programme. Families were continuing to make changes to improve the lives of people living with dementia six months later, suggesting IPSAF had a sustained impact.

Conclusion: This culturally adapted programme was found to have a significant impact on carers, the person with dementia and the wider family.

BACKGROUND

It is estimated there are currently 25,000 people from minority ethnic communities in the United Kingdom living with dementia, and this is predicted to increase to 1,720,000 by 2051 (APPG 2013; Wohland *et al.*, 2010). This would be a seven-fold increase in prevalence in 40 years compared to the two-fold increase predicted in the indigenous population. Despite the growing prevalence of dementia in minority ethnic populations, evidence suggests such groups remain under-represented in specialist dementia services (Moriarty *et al.*, 2011; Mukadam *et al.*, 2011; Cooper *et al.*, 2010; Purandare *et al.*, 2007). This may be due to lack of awareness of dementia in minority ethnic groups, with memory problems being viewed as a normal part of ageing (Giebel *et al.*, 2015; Johl *et al.*, 2014). Willis *et al.*, (2016), Parveen *et al.*, (2016) and Greenwood *et al.*, (2015) report a number of perceived barriers for minority ethnic communities accessing services, such as navigating complex social care pathways, language barriers, cultural stigma, lack of community-based services, concerns about cultural and religious appropriateness of services and culturally preferred coping strategies.

Due to the increasing evidence suggesting lack of awareness of dementia in minority ethnic communities, there have been a growing number of local initiatives aimed at improving awareness of dementia (Parveen *et al.*, 2015). Bhattacharyya and Benbow (2013) reviewed reports about 13 innovative services for older people from minority ethnic groups in the UK and made recommendations for practice including reaching out to communities, ensuring appropriate practitioner language skills, working in partnership with local black and minority ethnic (BME) organisations and ensuring initiatives are sustainable. The All Party Parliamentary Group's (2013) report 'Dementia does not discriminate' presented seven key recommendations for working with minority ethnic populations with dementia in the UK, including raising awareness of dementia and improving access to services for people with dementia.

Information programme for South Asian families (IPSAF)

In 2013, the Alzheimer's Society (a major national dementia charity in the UK) culturally adapted, in consultation with South Asian communities, an existing carers' information and support programme (CrISP) to develop an Information Programme for South Asian Families (IPSAF). CrISP was mainly attended by white British carers and the Society perceived the programme did not meet the cultural needs of south Asian families. The programme was adapted to be delivered in south Asian languages and included culturally specific examples. The aims of IPSAF are to improve the knowledge, skills and understanding of South Asian carers supporting a relative with dementia. The programme is delivered by an Alzheimer's Society facilitator in partnership with a local South Asian community organisation and consists of four sessions addressing understanding dementia, legal and money matters, looking after others and looking after yourself. As part of the implementation plan, the Alzheimer's Society planned to deliver IPSAF to nine sites across England, between September 2014 and March 2015. To evaluate the impact of their programme, the Society funded the external evaluation reported here. In this paper we report findings on the impact of the programme on the lives of those who attended and their wider families. In addition, we evaluated the success of the cultural adaptations of the programme, and the innovative model of partnership working (see Blakey *et al.*, 2016). The aims of the aspect of the evaluation reported here were to establish whether IPSAF:

1. had an immediate and/or medium-term impact on the lives of those carers/relatives who attended with regard to knowledge of dementia and/or use of services
2. had an immediate and/or medium-term impact on the wider families, including the person with dementia, of those who attended

METHOD

Participants

The evaluation was conducted across seven of the nine sites in England where IPSAF was delivered. Two further sites were unable to take part due to unforeseen delays in their start dates. All who attended IPSAF were invited to participate and we were able to cater for language requirements so that all could take part.

Procedure

Ethical approval was given by the University of Bradford's ethics committee in April 2014. A pluralistic, inclusive approach was adopted to address the aims including a knowledge quiz and focus groups with attenders (aim 1) and family interviews (aims 1 and 2). The research team attended two facilitator training sessions to inform the facilitators about the evaluation and address any concerns and queries. The facilitators shared information sheets and promotional material with those attending the programme to invite them to take part. The researchers then took formal consent from those who chose to participate.

Knowledge quiz:

In order to obtain a quantitative measure of change in participant knowledge of dementia and/or services, a social quiz was designed to overcome the linguistic and cultural barriers associated with a written questionnaire. This was conducted before the first and after the final sessions of IPSAF. Participants held up coloured numbered cards to show how much they agreed with each of six statements. The cards represented a Likert scale, from 1 (strongly disagree) to 5 (strongly agree).

Focus groups:

After the final session of IPSAF, attenders were invited to stay on to participate in a focus group with one focus group being held at each of the participating sites. Approximately 66%

of course attenders took part, with numbers ranging from 2 to 11. The focus groups were facilitated by two researchers, one of whom was multi-lingual, and discussion occurred in the language choice of participants (mainly Punjabi, Hindi, Urdu and English). Participants were asked about their views of IPSAF, whether it had impacted on their daily lives, what they had found useful, and whether and how it could be improved. The focus groups lasted 30 to 60 minutes.

Family interviews:

Attenders were also invited to participate in a family interview to include members who had not attended the course, and the person with dementia, if appropriate. Seven semi-structured family interviews were conducted in the participants' home. People with dementia were included where they had capacity to provide informed consent. Family size ranged from 1 to 5 with a mode of 2, and 3 people living with dementia took part. Relationships to the person with dementia were varied (three daughters and one son; son and daughter-in-law (2 families); two daughters; daughter and wife; wife; daughter-in-law and grand-daughter). Interviews lasted 25 to 100 minutes. Families were asked about the impact of IPSAF, whether and how knowledge had been shared with the family, changes for the person with dementia and how those who had attended IPSAF perceived the peer support aspect of the programme. Three of the families were followed up six months later to establish whether IPSAF had a sustained impact on the families. One family declined follow-up and due to timescales it was not possible to follow up the remaining three.

Data analysis

All interviews and focus groups were digitally recorded, translated, transcribed and analysed using thematic analysis (Braun and Clarke, 2006). Descriptive analysis was conducted on the

quantitative quiz data. The percentage of participants who strongly agreed/agreed with each statement was calculated and is presented in Figure 1.

FINDINGS

Demographic characteristics

The focus groups involved 42 participants of Indian, Pakistani and Bangladeshi heritage (See table 1). The majority were family carers, though 22 were not carers themselves but had an interest in how to support others in this role. Family interviews involved 17 participants, and included four families of Pakistani heritage and three of Indian heritage. Thirty seven participants completed the pre-quiz and 33 completed the post-quiz.

Insert Table 1 here

The immediate impact on those who attended IPSAF

All participants were very positive about the impact IPSAF had on their lives. This is discussed below under five themes: Knowledge and understanding of dementia, awareness and use of services, coping and confidence, social support, and emotional impact.

Knowledge and understanding of dementia

“You forget your daily tasks, how to make a simple cup of tea, we were shown how to make a simple cup of tea, how to do it, we actually did the task ourselves, how to make a cup of tea, it sounds simple but it isn't. I mean if you have dementia, it's not simple.” (Carer participant,

Focus group 4)

The participants demonstrated considerable evidence to suggest that IPSAF had increased their knowledge and understanding of dementia. Many reported that they had little or no understanding of dementia prior to the Course and had believed that dementia was part

of ‘normal ageing’. They now understood dementia as a disease with an organic cause. Participants discussed their knowledge of different types of dementia, their confidence in being able to recognise the signs and symptoms, and awareness of the causes. This new knowledge appeared to have given participants a better understanding of the person living with dementia, and many now felt more sympathetic and empathic towards them, where previously they had assumed certain behaviours of the person with dementia were deliberately done to cause irritation or gain attention. Despite the significant impact of IPSAF on understanding, some confusion persisted particularly with regards to causes of dementia. For example, two carers continued to believe that dementia was caused by stressful life events, and that dementia caused other health problems such as ‘aches and pains’.

The focus group discussions were supported by the data from the quiz (see Figure 1). Following IPSAF attendance, there was a 25% decrease in the number of participants perceiving dementia to be a natural part of ageing and a 41% decrease in the number believing that all people over the age of 80 years have dementia. In the pre-IPSAF quiz, 60% were aware that Alzheimer’s disease is a type of dementia and dementia is caused by a disease of the brain, with the proportion increasing to 75% post IPSAF.

Insert Figure 1 here

Awareness and use of services

“I feel less isolated because I know who the service providers are now, so kind of things to do with health, housing, legal issues. So we now know where to go because initially we kind of found these things by chance and by accident really, by asking people, you know”

(Carer Participant, Family interview 4)

All participants discussed being much more aware of services as a result of IPSAF and were able to give examples of services they could approach for support. Many placed particular value on knowledge gained about legal and financial aspects of supporting a person with dementia. There was considerable evidence that a number of participants had made use of services as a result of IPSAF, for example some reported making use of memory clinics; three reported applying for power of attorney as a result of what they had learned, five reported making use of their local Alzheimer's Society and several had contacted social services and completed carers' assessments. Attenders who were non-carers reported that they felt confident they could signpost carers to services, as a result of IPSAF. Although some carers reported that they were not planning on using services at the present time, they valued having the knowledge of available services. A number of carers expressed an intention but had not yet accessed more social types of support such as wellbeing cafés and carer support groups.

The quiz data (see Figure 1) supports these findings with the number of participants feeling confident they would be able to find support to help them tripling; and the number who perceived they would know where to go for advice on legal and financial matters doubling.

Coping and confidence

“We now understand that we need to make time for our self also a bit, so ok it's our duty to take care of our parents or husband, whoever is ill with the disease, we are devoted to that but the other important thing is I have to take care of myself also. If I get {a} cold, then who's going to take care of both of us” (Carer participant, Focus group 5)

An additional outcome was that almost all carers said they now better understood the need to look after themselves, one carer perceiving this ‘as the most important thing.’ Many

carers reported that IPSAF had validated the need for self-care and as a result felt less guilty. A significant number felt IPSAF had improved their understanding of the carer's role and given them confidence to support their relative with dementia. Some reported increased confidence in interacting with health care professionals, particularly as they felt more able to recognise the signs and symptoms of dementia. They also felt comfortable sharing information from IPSAF with their wider community. Two families reported feeling better able to cope with pressures from extended family members as a result of strategies they had learned.

Social support and emotional impact

“When you experience something which devastates you emotionally, you know, big time, it’s so important to find people in the same boat as you” (Carer participant, Family interview 1)

A number of participants reported that the peer group they had met during the Course had become a source of social support and they no longer felt they were ‘on their own’. Sharing and discussing their personal experiences with the group was seen as a form of ‘release’. Participants were very positive about the opportunity IPSAF gave them to discuss their experience with others who understood and could relate to the shared cultural barriers experienced, particularly with regards to seeking support. The group was seen as an opportunity to form connections, share information and learn from one another. However during family interviews, two carers reported that they had been hesitant to share personal experiences due to fear of judgement and confidentiality issues.

The immediate impact of IPSAF on wider family members including the person with dementia

“We understand that she can’t help forgetting things, but at the same time we are still trying to empower her, because we understand that, we still got to keep routine with her, to keep

her, to try and help her to keep remembering things, so we help with a lot of stuff, but we still empower her” (Carer participant, Family 1 interview follow up)

There was evidence from the family interviews to suggest that IPSAF had a significant positive impact on the lives of those with dementia. The knowledge and understanding gained by carers during IPSAF led to changes in how carers supported people with dementia. Many carers reported that they now, for example, used shorter sentences and pictorial aids to facilitate communication and some had developed a more organised routine for the person with dementia. Care practices were more centred on promoting independence and empowerment for those with dementia, who were provided with more choice of activities including a fresh opportunity to participate in previously enjoyed activities such as cooking.

IPSAF also had an impact on immediate family members who had not attended the Course, through knowledge-sharing facilitated by the Course leaflets and DVDs. These family members reported they now understood the person with dementia better and as a result behaved more supportively towards them. Families also discussed sharing information with extended family, friends and colleagues. One family discussed the limitations of receiving the information ‘second-hand’ and would have preferred to receive the information directly by attending IPSAF themselves. They also reported time as a barrier to sharing information with the wider family.

“When my sisters used to come back they used to ... share information, but it’s not the same as going into a course and then learning it yourself ... because sometimes the information that they would give you – these lot may forget [to tell] something but they’ll know it themselves; it’s better to go to the professional and just get it done” (Family member of course attender, Family interview 1)

The medium term impact of IPSAF

At the follow-up interviews, it was evident that the metaphors used in IPSAF to aid understanding of dementia continued to resonate with the families. The families had continued to provide more person-centred care and promote the person with dementia's independence. Information sharing with extended family members had continued and become more widespread, with examples of sharing information with neighbours and colleagues. One family had remained in contact with another that they had met through IPSAF and were supporting one another whilst sharing information. All three families had engaged with services in relation to seeking practical support, but had not accessed carer support groups. Although they were yet to attend carer support groups, the knowledge of their existence helped reduce their sense of isolation. Despite the families' improved awareness of services, they reported a number of barriers to access, for example the lack of local services, or no culturally specific services being available in their vicinity.

DISCUSSION

The findings provide support for the value of a culturally adapted carers' information programme for South Asian families, with those who participated in the evaluation reporting positive gains. The Course not only had a significant impact on those who attended but also appeared to bring benefits to the wider family and the person with dementia. Families' knowledge of dementia appeared to improve leading to a greater understanding of the person with dementia. This resulted in changes in care practices and styles, with families focusing on promoting independence and empowering the person with dementia, thus enhancing the person's quality of life. However the Course did not overcome some beliefs with regards to causes of dementia with some carers continuing to believe that stressful family events could be a cause. IPSAF was also found to have an impact on carer coping, validating the need for carers to look after themselves to continue to care effectively and providing much needed peer support. This latter aspect may be particularly important in south Asian communities,

given the isolation that may be experienced due to the high levels of stigma attached to dementia diagnosis and the lack of accessible culturally suitable services (Giebel *et al.*, 2015; Johl *et al.*, 2014).

Perhaps the most significant impact of IPSAF on families was their greater awareness of available services. Families made use of this knowledge to seek support with financial and legal matters. Some families continued to perceive barriers including lack of transport and culturally specific services in their area, and it was notable that none actually attended carer support groups. This strongly suggests that, as well as raising awareness of services, further work is required to provide a wider range of services that are specifically tailored to South Asian communities. The fact that this programme was well attended demonstrates that South Asian families do access services when these are designed and delivered in a culturally sensitive way, and in collaboration with local organisations.

There is some evidence that IPSAF had a sustained impact as families continued to develop a supportive environment for people living with dementia, and share information with the wider family and community thus contributing to much needed dementia awareness-raising which can lessen the stigma attached to having dementia.

The findings should be interpreted with care due to a number of limitations. The quiz was designed to provide a quantitative measure of knowledge to triangulate the findings from the focus groups. A self-completed questionnaire would have been culturally inappropriate for this particular group due to linguistic and literacy barriers in older generations and the quiz format had been found to be acceptable in previous work (Parveen *et al.*, 2015). Course facilitators were responsible for administering the quiz, which they found to be a challenge resulting in unusable data from two sites. Furthermore the influence of social desirability on

the responses cannot be discounted. It was not possible to conduct tests for statistical significance of changes due to the small sample size and lack of paired data.

The family interviews offered detailed insights into the impact of IPSAF on the wider family. However difficulties were encountered in ensuring all family members were available and willing to participate, and in retaining families for follow up. As only three families were followed up, this limits the evidence available to support sustained impact of IPSAF. The focus groups were a successful method, attracting 66% of Course attenders. Overall, the pluralistic approach overcame the limitations of individual methods and provided a thorough insight into the impact of IPSAF.

Despite the study limitations, the findings provide support that this culturally adapted information programme had a significant impact on South Asian families, with some evidence suggesting impact was sustained. IPSAF addresses recommendations for practice such as community engagement, ensuring cultural needs are met and working in partnership with BME organisations (Bhattacharyya and Benbow, 2013; Blakey *et al.*, 2016). The programme has the potential to have a positive impact on South Asian communities at national level, if embedded in care pathways, but also at an international level. Prince *et al.*, (2013) suggests that 58% of those living with dementia reside in low and middle income countries, with large increases in prevalence predicted in India, Bangladesh and Pakistan. IPSAF demonstrates potential as a service that could be implemented in South Asian countries to support families who are caring in the community for a relative with dementia.

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Table 1. The number of participants who attended IPSAF and participated in the evaluation

Site	Number of participants attended IPSAF	Number of participants in focus group	Number of females in focus groups
Site 1	5	3	3
Site 2	7	7	7
Site 3	16	9	8
Site 4	9	3	3
Site 5	8	7	7
Site 6	5	2	1
Site 7	14	11	7
Site 8	6	No focus group at this site	

Figure 1. *The percentage of participants that agreed with each statement pre and post IPSAF*

