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ORIGINAL ARTICLE

A peer outreach initiative to increase the registration of minorities as organ donors

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Abstract

Background: Black, Asian and minority ethnic (BAME) communities are disproportionately affected by inequalities in transplant services in the UK. There are some indications from pilot programmes that appeals for BAME organ donors may be more effectively communicated by employing grassroots, community-networking approaches, but such initiatives have not been adequately described or evaluated.

Methods: Lay individuals from BAME communities were trained as peer outreach workers. They attended a series of public events to promote knowledge of organ donation and transplantation among the public. Information was gathered from 806 evaluation forms completed by event attendees at 34 separate events. From these, 54 follow-up interviews were conducted with event attendees who completed evaluation forms, indicated that they intended to sign up to the NHS Organ Donor Register (ODR) within the next month and consented to follow-up.

Results: Peer outreach initiatives of the type evaluated are associated with increased numbers of BAME people registering as organ donors. A total of 8.8% of event attendees signed up to the NHS ODR. The programme was most effective with people who had previously considered becoming organ donors but who did not know how to go about it. It was less effective with people who had not previously considered it, or who were scared about signing up, or who feared family or religious disapproval.

Conclusions: Peer outreach programmes with BAME communities can be an effective way of reducing inequalities by increasing the number of people on the NHS ODR and encouraging people to think about the issue.

Key words: BAME, evaluation, organ donation, outreach, peer

Introduction

Black, Asian and minority ethnic (BAME) communities are disproportionately affected by inequalities in transplant services in the UK. They are at greater risk of developing organ failure, less likely to be organ donors and wait longer for transplants [1].

Prevalence of type 2 diabetes is up to six times higher among South Asian and African-Caribbean communities than in the white population [2, 3]. Both groups also have higher prevalence of hypertensive nephropathy [4]. Viral hepatitis—hepatitis B and C—is also more prevalent in the South Asian population, leading to increased likelihood of liver failure.

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While it is estimated that 10.8% of the current UK population is BAME, only 3.5% of ODR registrants are BAME [5]. Furthermore, while the number of white donors after death has risen significantly over the last 5 years there has been little change in the number of BAME donors (50 BAME kidney donors in 2012/2013) [5]. Relatives from BAME communities remain less likely to consent to donation following bereavement [6]. The percentage of patients from BAME background waiting for a kidney has gone up from 24% in 2008 to 30% in 2013. The acute shortage of suitable organs means BAME communities will wait on average 1 year longer for a kidney transplant than a white patient [5].

A number of studies have identified a range of barriers that prevent people from BAME communities from registering as organ donors. These include religious beliefs [7], fear that organs might be removed prior to death [8], fear that medical treatment might be withheld if the person is a donor [8] and a fatalistic attitude towards serious illness [8]. Randhawa [1] has added to this a lack of awareness among minority ethnic communities about the specific needs of their communities for organs.

The Organ Donation Taskforce [9] concluded that increasing the number of all organ donors should be an urgent requirement and that there should be a specific focus on BAME communities. In recent years, the UK Department of Health and NHS Blood and Transplant have produced a range of educational materials (including leaflets, posters and videos) in the main South Asian languages to increase awareness of transplantation-related issues, as well as launching some specific BAME-targeted campaigns. Materials have also been produced setting out the position of each religion regarding organ donation [1]. None of these approaches has had a conspicuous impact on the disparities between ethnic groups.

There are indications from pilot work in the UK and overseas involving minority ethnic groups that appeals for African-Caribbean and South Asian donors may be more effectively communicated by employing grassroots, community-networking approaches [10]. Such initiatives have not been adequately described or evaluated; however, Randhawa [1] argues that the evaluation of such community-based interventions should be a priority. Deedat's [11] systematic review of the best available evidence to determine the effectiveness of interventions to improve rates of registration and address poor knowledge about donation among ethnic minority populations highlights the lack of intervention studies focussing on ethnic minorities outside of the USA. This paper makes a significant contribution towards addressing the knowledge gap.

Materials and methods

Kidney Research UK launched the ABLE (A Better Life through Education and empowerment) programme in 2001 to raise awareness of kidney disease in BAME communities. As part of this, a peer outreach programme was piloted in Harrow (Middlesex) in 2009 and subsequently rolled out to Hounslow, Lewisham and Lambeth in 2010 (all in London, UK). The programme aimed both to raise awareness of the issues surrounding organ donation for BAME communities and to increase the numbers of BAME people on the NHS ODR.

The peer outreach workers (POWs) were lay people, drawn from local BAME communities, with a passion for promoting health and a natural empathy in terms of language, culture and religion. They included an Indian Hindu male; a Somali Muslim male; a Nigerian Christian female; a Kenyan Muslim female; a Hindu female; a Gujarati Jain and an Indian Hindu female. All were aged forty or above. They received 2 days training which detailed the extent of the problem faced by BAME groups in relation to both their high risk of requiring donated organs and the severe shortage of BAME donors. The training was accredited at 'level three' with the Open College Network. They were also given additional training on presentation skills.

The peer outreach programme involves education and awareness-raising which is directed at BAME groups. A range of specific venues and community events are targeted in order to maximize engagement with BAME communities. Examples of the type of events attended by the Peer Educators include an Asian bridal show, a public library and a yoga class for South Asian elders.

Generally, the peer outreach programme takes two forms: in larger settings, a stand, which is typically staffed by two POWs, is positioned in a prominent position, such as an entrance foyer. Posters and leaflets are also displayed to attract people to the stand. These include informational leaflets specifically targeted at BAME groups and minority faith groups in different languages. Alternatively, and usually in smaller settings, presentations may be given to small groups. During both the larger and smaller events, the programme seeks to provide relevant information and attempts to address misconceptions about donation while at the same time encouraging members of BAME communities to register on the NHS ODR (facilities for registering are provided by the POWs at the events). The team has developed a quiz which is used as an ice breaker and as a way of opening up a discussion about organ donation.

While the intervention at any event may vary (for example, according to the nature of the event, the number of attendees, whether there is scope to deliver a presentation etc.) the general approach is consistent—that is, one of using lay POWs from BAME communities to proactively approach other members of BAME communities in community settings to engage them in discussions about organ donation and encourage them to sign up to the NHS ODR. Central to the approach is the person-to-person contact which allows specific and personal concerns around, for example, religious objections, to be discussed. At one event, for example, a POW was able to share a fatwa issued by the Sharia Council in the 1990's affirming that organ donation was allowed and should be seen as a positive step with in a Muslim population group.

The evaluation was completed by a team of researchers from the School of Social Work at the University of Central Lancashire, with financial support from the Department of Health.

Information was gathered from an evaluation form completed by event attendees after they had visited the stand and/or listened to a talk about organ donation delivered by the POWs. A total of 806 evaluation forms were returned from 34 separate events held in a range of community settings including libraries, schools, places of worship, community centres and exhibition spaces.

Follow-up interviews were conducted with all ($n = 54$) event attendees who indicated both (i) that they intended to sign up to the NHS ODR within the next month after they had had time to think about it and (ii) that they were happy to be followed-up.

Ethical governance was provided by the ethics committee at the International School for Communities Rights and Inclusion, University of Central Lancashire (study number 10/023).

Analysis was conducted using IBM SPSS Statistics (version 19). Statistical significance was tested for using Fisher's exact test.

Respondents were asked to self-define their ethnicity and they did so using more than 50 different categories. For the purpose of analysis, these categories have been grouped together so that, for example, the category Asian includes those who defined themselves as Asian, Asian from Africa, Asian Hindu, Asian Indian, Asian Muslim, Bangladeshi, Bengali, British Asian, British

Indian, British Pakistani, Indian, Nepalese, Pakistani, Punjabi, Sri Lankan, South Asian or Tamil.

Results

The majority of respondents were Asian (*n* = 402/574: 70%). Most respondents were aged between 31 and 50 (*n* = 435/778: 56%) and more respondents were female (*n* = 450/772: 58%) (Table 1).

Only 13.7% (*n* = 110/804) of event attendees reported that they had already signed up to the NHS ODR, confirming earlier findings that BAME populations are less likely than the whole unselected population to be registered as organ donors [12].

Seventy-one percent (*n* = 57/80) of those who had already signed the NHS ODR and on whom ethic group information was known were Asian (Table 2). While the sample sizes of some ethnic groups was small making statistical analysis difficult, the 57 Asian respondents who had already signed up to the NHS ODR represent 14.2% of all Asian respondents, whereas only 7.1% (*n* = 8/113) of Black African/African Caribbean respondents had previously signed up (P = 0.053).

Older respondents (aged 51 or above) were more likely to have already signed up to the register than those aged 50 or under (18.1% compared with 12.3%: P = 0.061) (Table 2), but these figures are difficult to compare against national figures as NHSBT only reports the ages of donors when they *join* the register. Nationally, 30% of people on the NHS ODR are aged between 16 and 25 when they join. A further 24% are aged between 26 and 35 and 9% are 65 or over [13]. The age profile of people who have donated organs after death has changed over the past decade with more aged over 50 and fewer younger donors.

15.1% of women (*n* = 68/450) had signed up to the NHS ODR prior to the programme, compared with 12.1% of men (*n* = 39/322) (P = 0.247) (Table 2). Although our data do not show a statistically significant difference, previous research has shown that women are more likely to be organ donors than men [14–16].

Table 1. Ethnicity, ages and gender of respondents

	Number	Percent
Ethnicity		
Asian	402	70.0
Black African/African Caribbean	113	19.7
White	13	2.3
Mixed	8	1.4
Other	38	6.6
Valid total	574	100.0
Missing	232	
Total	806	
Age group		
<18	3	0.4
18–30	163	21.0
31–50	435	55.9
51–70	148	19.0
70+	29	3.7
Valid total	778	100.0
Missing	28	
Total	806	
Gender		
Male	322	41.7
Female	450	58.3
Valid total	772	100.0
Missing	34	
Total	806	

Of the 110 event attendees who had already signed up to the NHS Organ Donor Register, 90 (84%) had spoken to their next of kin about their wishes.

The impact of the programme

On increasing the numbers of people from Black and minority ethnic communities who signed up to the NHS Organ Donor Register on the day of the programme

A total of 8.8% (*n* = 58/662) of those respondents who had not already signed up to the NHS Organ Donor Register did so on the day of the programme.

Asian people were more likely to sign up on the day of the programme when compared against all other groups (11% compared with 2.8%: P = 0.003) (Table 3).

Older respondents (that is, those aged 51 and above) were more likely to sign up on the day of the programme than those aged under 50 (11.8% compared with 6.0%: P = 0.025) (Table 3), with those aged 71 or above being the most likely (19% P = 0.029). The percentage of men who signed up on the day of the programme (10.3%) was slightly greater than the percentage of women who did so (7.5%) (P = 0.254).

Of those who had not previously signed up but who did so on the day of the programme, most (75%; *n* = 42) had previously considered signing. This contrasts with those who did not sign up on that day, most of whom (71.7%: *n* = 424) had not considered signing up previously (P < 0.001).

Reasons given by respondents for why they had not previously signed up

The main reasons given by respondents for why they had not previously signed up are set out in Table 4. The reasons given

Table 2. Percentage of respondents who had already signed up to the Organ Donor Register by ethnic group, age and gender

	Number from group who had already signed up	Number from group in sample	Percent
Ethnic group			
Asian	57	402	14.2
Black African/ African Caribbean	8	113	7.1
White	8	13	61.5
Mixed	1	8	12.5
Other	6	38	15.8
Missing	30	232	12.9
Total	110	806	13.6
Age group			
<18	0	3	0.0
18–30	20	163	12.3
31–50	54	435	12.4
51–70	26	148	17.6
70+	6	29	20.7
Missing	4	28	14.3
Total	110	806	13.6
Gender			
Male	39	322	12.1
Female	68	450	15.1
Missing	3	34	8.8
Total	110	806	13.6

Table 3. Whether respondents who had not previously signed up to the Organ Donor Register did so on the day of the programme by ethnic group, age and gender

	Did not sign up		Did sign up		Don't know/ missing
	Number	Percent	Number	Percent	
Ethnic group					
Asian	291	89.0	36	11.0	17
Black African/ African Caribbean	98	98.0	2	2.0	5
White	5	100.0	0	0.0	2
Mixed	4	80.0	1	20.0	2
Other	30	96.8	1	3.2	1
Missing	176		18		7
Total	604		58		34
Age group					
<18	3	100.0	0	0.0	0
18–30	123	91.1	12	8.9	8
31–50	337	88.7	28	7.7	15
51–70	103	89.6	12	10.4	7
71+	17	81.0	4	19.0	2
Missing	21		2		2
Total	604		58		34
Gender					
Male	243	89.7	28	10.3	12
Female	334	92.5	27	7.5	20
Missing	27		3		2
Total	604		58		34

by those who did sign up on the day of the programme and those who did not sign up on that day are different. While for both groups the biggest barrier was not knowing enough about it (39.4 and 41.2%, respectively: P = 1.000), for those *who did not sign up on the day of the programme*, being scared (22.6%), or having concerns about religious (17%) or family (13.4%) approval featured as more significant concerns (P = 0.027, 0.029 and 0.015, respectively). For those *who did sign up on the day of the programme*, not knowing how to go about it was a more important barrier than for those *who did not sign up on the day* (30.3% compared with 8.6%: P = 0.001).

How the programme was received

While both groups rated the quality of information that they received on the day of the programme highly (all of those who signed up on that day rated it as good or excellent, as did 94.9% of those who did not sign up on the day, P = 0.242), those who signed up on that day of the programme rated the information more highly, although this did not achieve statistical significance. A higher proportion rated it as excellent (56.4% compared with 43.9%: P = 0.178) and none rated it as average (P = 0.242) (Table 5).

Respondents who signed up to the NHS ODR on the day of the programme showed no significant difference in how much they had learned compared with those who did not. However, a greater proportion of those who signed up on that day also agreed that their attitude towards organ donation had changed (70.3% compared with 51.9%: P = 0.039). Respondents who signed up on the day of the programme were also more likely than those who did not do so to strongly agree with the statement that they felt more able to talk to their family about organ donation (75% compared with 58.3%: P = 0.053).

Table 4. Reasons given by respondents for why they had not signed up before[a]

Reasons for not having signed before	Did not sign up		Did sign up	
	Number	Percent	Number	Percent
I don't know enough about it	215	41.2	13	39.4
I don't know how to go about it	45	8.6	10	30.3
It scares me	118	22.6	2	6.1
I don't agree with it	32	6.1	2	6.1
My religious beliefs forbid it	89	17.0	1	3.0
My family don't approve	70	13.4	0	0
Other	77	14.8	4	12.1
Missing	82		25	

[a] It was possible for respondents to give more than one answer.

Table 5. How respondents rated the information that they had received

Rating	Did not sign up		Did sign up	
	Number	Percent	Number	Percent
Excellent	191	43.9	22	56.4
Good	222	51.0	17	43.6
Average	22	5.1	0	0
Poor	0	0	0	0
Valid total	435	100.0	39	100.0
Missing	169		19	
Total	604		58	

Impact at follow-up

A total of 25.2% (n = 102/405) of respondents who did not sign up on the day of the programme indicated that they would do so within the next month. Fifty-four of these indicated that they were willing to be contacted and followed-up later to see if they had in fact done so. All were contacted and interviewed over the phone 3–4 months after the event to see if they had signed up to the NHS Organ Donor Register, but none of them had, with most of them saying that they still needed further time to think.

Discussion

Peer outreach initiatives may be effective in encouraging those who have previously thought about signing up to the NHS ODR to do so—but this is only clear if they sign up on the day of the programme. They are unlikely to have any effect (within 3–4 months) on those who think that they may sign up at a later date, although we cannot discount the possibility that exposure to peer outreach may make them more likely to agree to sign up to the NHS ODR if they are approached again, especially given the finding that those who had previously thought about signing up to the NHS ODR were more likely to do so than those who had not.

This evaluation confirmed the under-representation of BAME on the NHS Organ Donor Register. Only 13.7% (n = 110/804) of event attendees reported that they were already signed up to the NHS ODR prior to the intervention. This compares with a figure for the UK population as a whole of 29%. Peer Educator programmes such as this can have an impact in terms of increasing the number of people from BAME communities who sign up to the NHS ODR. A total of 8.8% ($n = 58/662$) of those who attended the programme signed up to the NHS ODR on the day of the programme. Despite this, however, the total proportion of attendees from BAME communities who were signed up to register after the events (20.9%) remained below that for the population as a whole (29%).

The programme as it was run was particularly successful at reaching Asian people, who were also more likely than other groups to sign up to the NHS Organ Donor Register as a result. This may have been due to the age and ethnic profile of the POWs: factors such as the age, gender and ethnic origin of the POWs and the types of venues and events that are visited are likely to have an impact on the type of person that the programme reaches. Future programmes should consider ways of reaching other ethnic groups, younger people and men. Differences (for example, in terms of cultural and religious and ethnic identity) both within and across BAME communities need to be borne in mind when developing programmes. The percentage of Black African/African Caribbean respondents who had signed up previously was low ($n = 8/113$; 7%) and the programme did not appear to have an impact on Black African/African Caribbean respondents, only two of whom (out of 100 Black African/African Caribbean event attendees) signed up on the day of the programme.

In future evaluations, it would be useful to collect data in such a way as to allow further analysis to understand whether certain types of events (for example, smaller ones where the ethnicity and age of POWs is matched to that of event attendees) achieve better results.

Since one of the potential barriers to organ donation is the refusal of next of kin to give consent after the death of the potential donor, it is encouraging that in most instances respondents said that their next of kin was aware of their wishes. In order to improve outcomes, future peer outreach initiatives might consider actively discussing with potential donors whose next of kin were not aware why this was the case and encouraging and supporting potential donors to have this discussion. It is also encouraging that 75% ($n = 27/36$) of those who signed up to the NHS Organ Donor Register on the day of the programme agreed or strongly agreed that they felt more able to talk to their family about organ donation.

The programme was well received by all respondents regardless of whether or not they signed up to the NHS Organ Donor Register on that day. The programme had its biggest impact—not only in terms of getting people to sign up on the day of the programme but also in terms of how much respondents felt they had learned, whether they felt that their attitudes had changed and whether they felt more able to talk to their family members about organ donation—on those who did sign up on that day. This is important as it begins to offer some clues as to how the programme works not only in terms of affecting behaviour (i.e. whether participants sign up) but also in terms of affecting some of the knowledge and attitudes that underpin such behaviour. Deedat [11] suggests that educational interventions are more likely to be successful when combined with a strong personal component and an immediate opportunity to register. Even respondents who did not sign up on the day of the programme rated the information that they received highly and felt that they learned more about organ donation, even if their attitudes and behaviour did not change. Given the finding that the programme had a significantly bigger impact in terms of getting people to sign up on that day where respondents had previously already thought about signing up to the register ($P < 0.001$), the changes that occurred in learning about organ donation among respondents who did not sign up on that day but who indicated that they may do so at some later stage are important. These may be the very people who will sign up if they are approached again. It is therefore important that peer outreach programmes are repeated and not simply run as one-off events.

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Authors' contributions

J.B. contributed to the design of the study, was responsible for data analysis, for interpretation of the data and for production of an initial draft paper. He was also responsible for producing the final draft, which was approved by all authors. R.L. contributed to the design of the study, was responsible for data analysis, for interpretation of the data and for production of an initial draft paper. N.J. contributed to the design of the study and was responsible for reviewing the draft article critically. A.W. contributed to the design of the study and was responsible for reviewing the draft article critically.

Conflict of interest statement

None declared.

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