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What are effective approaches to increasing rates of organ donor registration among ethnic minority populations: a systematic review

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ABSTRACT

Objectives: To identify effective interventions to increase organ donor registration and improve knowledge about organ donation among ethnic minorities in North America and the UK.

Design: Systematic review.

Data Sources: MEDLINE, EMBASE, PsycINFO, CINAHL and Cochrane Central searched up to November 2012, together with four trials databases and the grey literature.

Review methods: A systematic search followed by assessment of eligibility and quality. An interpretive and thematic approach to synthesis was undertaken. This examined the nature and delivery of interventions in relation to a range of outcomes: verified registration, changing knowledge and a measured shift towards greater readiness.

Results: 18 studies were included in the review, comprising educational and mass media interventions. Mass media interventions alone reported no significant change in the intention or willingness to register. Educational interventions either alone or combined with mass media approaches were more effective in increasing registration rates, with a strong interpersonal component and an immediate opportunity to register identified as important characteristics in successful change.

Conclusions: Effective interventions need to be matched to the populations' stage of readiness to register. Measured outcomes should include registration and shifts along the pathway towards this behavioural outcome.

Strengths and limitations of this study

- The first systematic review of evaluated interventions to increase organ donor registration and knowledge of organ donation among minority ethnic groups.
- The review examines both the outcomes achieved and issues of implementation to identify how and under what conditions a particular approach can be implemented to maximum effect.
- The number of evaluated interventions is currently small, with considerable variability in the study design, measures and outcomes assessed.

BACKGROUND

There has been increasing debate in the UK regarding the merits of a potential shift towards a system of presumed consent for deceased organ donation to close the gap between the supply of organs for transplant and the numbers of organs required to meet the increasing demand.[1] This gap is particularly significant for members of ethnic minority populations. In the UK, Black and South Asian individuals constitute 8.4% of the population[2] but represent 4% of organ donors for whom ethnicity is recorded and 20% of the active kidney transplant waiting list.[3] Similarly, in the USA, African Americans account for 13% of the population but constitute 34% of those waiting for a kidney,[4] while overall ethnic minorities account for 56.3% of those waiting for a transplant in the USA.[5]

The high level of unmet need for transplantation among British and American ethnic minority populations is influenced by increased risks of end-stage renal failure and thus a high need for kidney transplantation among minority ethnic groups. This low donation rate is of particular significance given the greater prevalence among minority ethnic groups of blood groups and human leucocyte antigen types that are less common in the general population. The donation rate among minority ethnic groups has in turn been shown to be influenced by a number of modifiable barriers, including lack of knowledge of the need for donors and how to register as a donor, less favourable cultural and religious beliefs, and a lack of trust in health professionals and the fairness of the organ allocation system.[6]

The UK's Organ Donation Taskforce recognised an urgent need to identify and implement the most effective methods to promote organ donation and registration to the public generally and ethnic minority populations specifically.[7] However, despite mass media campaigns and some community engagement activities, the proportion of the population on the Organ Donor Register has only increased from 25% in 2008 to 30% in 2012, while the actual number of minority ethnic registrants remains small.[8]

This review systematically assesses the best available evidence to determine the effectiveness of interventions designed to improve rates of registration and address poor knowledge to donation among ethnic minority populations. It also examines issues of implementation and seeks to identify how, where and under what conditions a particular approach can be implemented to maximum effect.

METHODS

Systematic search

The following databases were initially searched in December 2009 and refreshed in November 2012: MEDLINE, EMBASE, PsycINFO, CINAHL and Cochrane Central. Trials databases were also searched for relevant studies as was the academic and grey literature using search engines, hand checking relevant publications and direct contact with experts in the field (box 1).

The inclusion criteria focused on intervention studies in North America and the UK that were designed to change the rates of registration, intention/willingness to become a donor or knowledge about organ donation and focused on visible ethnic minorities (box 1).

Box 1 Systematic search

1. *Sources*
   Databases searched: MEDLINE (Ovid), EMBASE (Ovid), PsycINFO (Ovid), CINAHL (Ebso), Cochrane Central Pubmed
   Trials databases searched:
   UKCRN, ClincialTrials.gov, WHO international Clinical Trials Registry Platform and Health Service Research Projects in Progress.
   Websites searched for in the grey literature:
   National Health Service Blood and Transplant—http://www.nhsbt.nhs.uk
   Department of Health (UK)—http://www.dh.gov.uk
   Kidney Research (UK)—http://www.kidneyresearch.org.uk
   US Department of Transplant (funded studies) http://www.organdonor.gov/dtcp/behavior.html
2. *Inclusion critera*:
   Country: UK, USA
   Date of publication: 1980–2012
   Ethnicity: Visible ethnic minority
   Design: Intervention study, evaluation study
   Outcomes: Verified registration, willingness/intent to register, change in registration rates
   Participants: Adults and school age children
   Setting: Community
   Full search terms are available in the online supplementary material.

A scoping search was initially run in MEDLINE and then further developed, revised and rerun and subsequently adapted for alternative databases. Ethnicity was defined as a visible (non-white) ethnic minority, with specific ethnic categories being those attributed, with a range of terms required to identify the appropriate ethnic minority populations. Table 1 provides an overview of included studies and the databases from which they were identified.

Relevance and quality assessment

Following initial deduplication, 557 articles remained (see figure 1). Two authors (SD and CK) independently reviewed the title and abstract of all citations identified and applied the exclusion criteria. Where information was not sufficient, the full article was retrieved for review. Where interventions were not targeted specifically at ethnic minorities, studies were included if subgroup analysis by ethnicity was conducted. Studies were excluded if they did not include original data or reported a meeting abstract only. Articles rejected at this stage were mainly cross-sectional studies that did not report an intervention to either increase registration or address knowledge gaps about organ donation in ethnic minority populations.

Two members of the research team independently scored the included articles for quality (SD and MM). Quality assessment was guided by the 'Assessment Tool for Quantitative Studies' (http://www.city.hamilton.on.ca/phcs/EPHPP), recommended by the Cochrane Handbook for the quality assessment of reviews in public health and health promotion. This tool is applicable to randomised controlled trials, quasi-experimental studies and uncontrolled studies[9] and both content and construct validity have been established.[10] Using this assessment tool, five articles were rated as 'strong', having four or more of the six components rated as strong with no weak ratings, and were all cluster randomised trials. Ten studies were 'moderate' with less than four components rated as strong and one as weak, and three articles had two or more components rated as 'weak' and were scored as such. Critical reflection on the quality review process led us to also consider complementary criteria set out by the Medical Research Council for the development and evaluation of complex interventions.[11] This led to further assessment of theoretical quality in terms of how the intervention was expected to cause change and the quality of implementation in terms of whether there was standardisation of delivery through study design and/or facilitator training (see table 2).

Data synthesis

Wide variations in outcomes, populations and study design of included studies precluded meta-analysis. An

Table 1 Overview of studies included in the review

Author and country	Demographics sample size (n)	Study design	Mode of delivery	Results	Outcomes	Theoretical framework	Database
Education							
Allen and Stillwater,[26] USA	Alaskan native N=54 Health staff N=<200 students	Before and after study	PowerPoint presentation and video focused on issues about OD and Alaskan natives	Improved knowledge and positive attitude towards donation and intention to register post test	Knowledge and intention to register as a donor	Not mentioned	Hand search of book
Alvaro *et al*,[20] USA (pertains to study II reported in paper)	Hispanic	Before and after study	On alternate weeks, employees of the local organ procurement organisation offered the attendees at a flea market an immediate opportunity to register or information about organ donation	Participants offered an immediate opportunity to register rather than just information about OD were significantly more likely to register (86% vs 54%)	Verified registration	The IFF model (Immediate opportunity, information, focused engagement and favourable activation)	MEDLINE
Andrews *et al*,[13] USA	African American Intervention n=622 Control n=632	Cluster randomised	Members of the congregation undertook discussions with lay health advisors about organ donation. DVD designed to address OD barriers for African Americans	Increase in verified enrolment on donor registry in intervention group. No increase in knowledge observed	Verified enrolment on donor registry	Not mentioned	PubMed
A Warrens, personal communication, 2013 UK	Multiethnic N=806	Cross-sectional evaluation	Peer educators trained to deliver health promotion about OD	Increase in the percentage of people signed up to the organ donor register	Registration	Not mentioned	Author contact
Callender *et al*,[25] USA	Multiethnic N=914	Before and after study	Presentation about organ donation delivered by transplant recipients, donors, individuals on transplant lists healthcare professionals who are ethnically similar to the target population.	Improvements in knowledge and attitudes towards OD, high reporting of willingness to discuss OD with family	Willingness to donate organs for oneself and loved ones after death No valid measures to assess attitudes to OD	Not mentioned	EMBASE
Thornton *et al*,[17] USA	Multiethnic Intervention n=443 Control n=509	Cluster randomised	5 min Video about OD prior to collecting driver's licence. Controls obtained	Cases more likely to register as donors compared to controls (76% vs 54%)	Verified enrolment on donor registry	Not Mentioned	EMBASE

Continued

Table 1 Continued

Author and country	Demographics sample size (n)	Study design	Mode of delivery	Results	Outcomes	Theoretical framework	Database
			licence in the usual manner.				
Fahrenwald *et al*,[28] USA	American Indians N=1580	Before and after study	Out-reach coordinators facilitate delivery to small groups who were required to read and discuss a 1 page brochure. This was followed by a 13 min video and a group discussion facilitated by the coordinator	Significant change in stage of motivational readiness to become an OD postintervention	Stage of motivational readiness to serve as an organ donor	Transtheoretical model of behaviour change	PubMed
Resnicow *et al*,[12] USA	African American Intervention n=1370 Control n=1419	Cluster randomised	Hairstylists trained as lay health advisors used motivational interviewing to discuss OD with participants	Participants receiving the intervention were 4 times more likely to join the register than the controls	Self-reported donation status Verified enrolment on state registry	Not Mentioned	PubMed and EMBASE
Salim *et al*,[24] USA	Hispanic N=341	Before and after study	Presentation about the need for transplant and information about donation lead by a local organ procurement organisation	Increase in knowledge, perceptions and beliefs. No difference willingness to discuss donation with family or intent to donate	Change in knowledge and attitude Donation intent	Not mentioned	PubMed
Cárdenas *et al*,[18] USA	Multiethnic Intervention n=96 Control n=91	Cluster randomised	Transplant surgeons and young recipients gave a presentation followed by a Q&A session and a video	Knowledge increase postintervention was the strongest predictor of positive change in opinion about OD	Knowledge, attitudes and awareness of OD	None mentioned	MEDLINE
Feeley *et al*,[19] USA	Multiethnic	Before and after study	Peer educators delivered a range of campus-based activities	Increased donor registration	Self-reported registration	Not mentioned	Embase, MEDLINE, PubMed
Arriola *et al*,[14] USA	African American Intervention n=175 Control n=162	Cluster randomised	Video and written materials mailed to participants	Greater readiness to sign a donor card, register through a driver's licence or talk to family about wishes in the intervention group	Readiness to express donation intent through a driver's licence, donor card and discussion with family	Transtheoretical model of behaviour change	EMBASE, PubMed and MEDLINE
Media							
Alvaro *et al*,[31] USA	Hispanic N=2401	Before and after study	4×30 s television 2×60 s radio ads.	Greater reporting of prodonation beliefs and	Self-reported registration status	Not mentioned	

Continued

Table 1 Continued

Author and country	Demographics sample size (n)	Study design	Mode of delivery	Results	Outcomes	Theoretical framework	Database
			These highlighted positive impact of transplant on Hispanic individuals and demonstrated the substantial efforts medics undertake to save the life of a potential donor	family discussion postintervention	No validated measures of attitude and willingness to OD		EMBASE and MEDLINE
Frates *et al*,[29] USA	Hispanic N=4500	Before and after study	Prime time television and radio slots	Year on year increase in Hispanic OD consent rates (overall 10% increase). Increase in knowledge/attitudes	Consent rates from organ procurement organisation No valid measures to assess attitudes to OD	Transtheoretical model	EMBASE, MEDLINE and PsycINFO
Salim *et al*,[30] USA	Hispanic N=1052	Before and after study	Prime time television and radio slots	Improved knowledge postcampaign when compared to baseline	Awareness, perception and belief about OD	Not mentioned	EMBASE and MEDLINE
Radosevich *et al*,[16] USA	African American N=465	Before and after study	Media campaign conveyed through television, radio, targeted print media. Donor families and healthcare professionals were interviewed on television and radio	Significant increase in knowledge and attitude about organ donation postcampaign No significant change in intention and willingness to become a donor	Self-reported registration Change in knowledge, attitudes and willingness to become a donor	Theory of Reasoned Action	Hand Search of Book
Media and education							
Harrison *et al*,[15] USA	African American N=626 771	Before and after study	Billboards in the vicinity of vehicle licensing offices and radio adverts. Trained volunteers with links to donation at vehicle licensing offices to engage in conversation	Overall 700% increase above baseline in sign up to the donor register. The magnitude of the increase was greatest when one-to-one promotion was combined with other medium	Verified registration	Communication design	PubMed
Hebert *et al*,[32] USA	Chinese American N=1134	Before and after study	Media campaign Grass roots community outreach	Significant increase in stated intention to donate in the intervention area vs the control area	Joining a donor registry Express a desire to become an organ donor Communicating wishes to family	Not mentioned	Hand search of book

OD, organ donation; Q&A, question and answer.

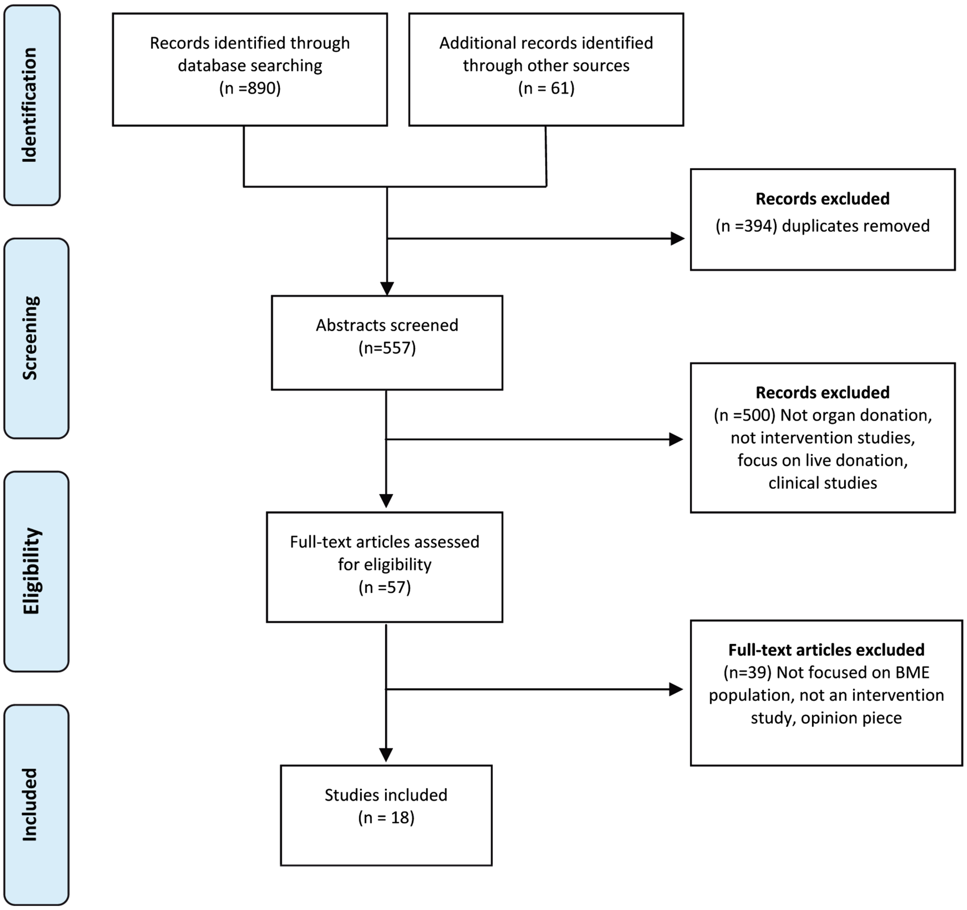

Figure 1 Selection of studies for inclusion in systematic review of interventions to increase organ donor registration among ethnic minority populations.

interpretive and thematic approach to synthesis was therefore undertaken and examined the nature and delivery of interventions as well as the outcomes achieved. Studies were initially classified by: date, country, population studied and intervention type and study design. The second step involved classifying the media and education interventions in terms of the aims of the interventions and the outcomes achieved. Third, we examined the relationship between characteristics of the interventions from the outcomes. Data were extracted into tables and these were verified by two of the authors (SD and MM).

RESULTS

Study characteristics

The 18 included studies were conducted between 1993 and 2012. These either evaluated the effects of an ethnically targeted mass media campaign or community-based education. With the exception of one UK study, all were undertaken with ethnic minority populations in the USA, mainly African Americans or Hispanics.[12–16] Whereas most interventions adopted a pre-evaluation and postevaluation design (table 1), studies published since 2009 mainly employed a cluster randomised design.[12–14 17 18] Outcomes assessed were verified registration, self-reported registration status or knowledge about organ donation (see table 1).

Educational interventions

Eleven articles reported educational interventions. Recruitment was mainly through or conducted at places of worship and/or educational establishments, and delivered by a range of individuals including recipient families, trained lay individuals or organ transplant and procurement staff. Six studies were designed for a specific ethnic group, with the remainder aimed at a multiethnic audience (see table 2)

Verified registration

Three cluster randomised trials reported an outcome of verified enrolment on a donor register.[12 13 17] Two of these studies trained individuals embedded within community settings to deliver the intervention,[12 13] with both these interventions having a strong interpersonal element and being delivered in familiar settings of a local church or hairdresser. Peer educators in Andrews' study[13] mostly had a medical background and were involved in a Church Health Committee. They undertook a 4 h training package that comprised general information about

Table 2 Assessment of included studies based on two components of the Medical Research Council[11] criteria for complex interventions

Authors	Theoretical quality	Standardisation of delivery
A Warrens, personal communication, 2013	Minimally grounded	Authors allow for and explain variation in intervention delivery Standard training offered to educators delivering intervention
Allen and Stillwater[26]	Minimally grounded	Authors indicate variation
Alvaro *et al*[31]	Moderately grounded	Strict standardisation (due to intervention design)
Alvaro *et al*[20]	Well grounded	Strict standardisation—authors undertook unannounced site visits and developed standard reporting tools for completion at intervention sites
Andrews *et al*[13]	Moderately grounded	Authors indicate variation
Arriola *et al*[14]	Well grounded	Strict standardisation
Callender *et al*[25]	Well grounded	Authors indicate variation
Cárdenas *et al*[18]	Moderately grounded	Strict standardisation
Thornton *et al*[17]	No theoretical grounding	Strict standardisation
Fahrenwald *et al*[28]	Well grounded	Strict standardisation
Feeley *et al*[19]	Moderately grounded	Authors allow for and explain variation
Frates *et al*[29]	Moderately grounded	Strict standardisation (due to intervention design)
Harrison *et al*[15]	Well grounded	Strict standardisation of media and print info. Variation but no explanation or assessment of variation in interpersonal elements
Hebert *et al*[32]	Moderately grounded	Strict standardisation (due to intervention design)
Radosevich *et al*[15]	Moderately grounded	Strict standardisation due to intervention design)
Resnicow *et al*[12]	Moderately grounded	Strict standardisation. Standard training offered to educators delivering intervention
Salim *et al*[30]	Minimally grounded	Strict standardisation (due to intervention design)
Salim *et al*[24]	Minimally grounded	Strict standardisation

organ donation and tips on integrating the topic into church discussions. In Resnicow's study,[12] hair stylists were trained over 2 days in practical techniques to facilitate communication (motivational interviewing) and general organ donation information. There were wide variations in the duration of these study interventions: participants in the Church study were exposed over a period of 12 months, while interventions with a hair stylist ran for 1 session/month for 4 months. In contrast, the third intervention in this category did not have a strong interpersonal element, and trialled the use of a 5 min educational film to address common barriers to organ donation that was targeted at those attending the state vehicle licensing office.[17] Across all three interventions, the exposed group were significantly more likely to register than the controls, although the effects of the video intervention among vehicle licensing office attendees were significant for White and African Americans but not Hispanic participants,[17] possibly reflecting their small number (n=−28).

Further, three community educational studies based on a follow-up or cross-sectional design reported strategies to increase organ donor registration. Feeley *et al*[19] reported a 1.6% increase in new organ donor registrations following campus-led peer education among students from six university campuses in the USA that were selected as having a high percentage of minority student enrolment. Similarly, a study in Arizona focused on Hispanics attending a large community event found that advertising and offering an immediate opportunity to register produced significantly greater registration rates compared with the use of a generic slogan and offering general information about organ donation (86% vs 54%).[20] A further UK community-based educational intervention study focused on attendees at a range of venues and community events selected to maximise engagement with Black and minority (BME) communities (A Warrens, personal communication, 2013). The authors report that following discussion with a trained BME Peer Educator and the availability of facilities for

Table 3 Absolute difference (95% CI) between intervention and control groups for verified registration across ethnic groups

			African American	Hispanic
Study	**Target population/setting**	**Intervention**	**Absolute difference (CI 95%)**	
Resnicow *et al*[12]*	*African American setting*: Hair Dressers	*Intervention:* Brief motivational intervention delivered by hairdresser	*2.8 (2.2 to 3.2),* p<0.0001	
Thornton *et al*[17]	*All ethnic groups including white setting*: outside motor Vehicle registration office	*Intervention:* 5 min video addressing ethnic concerns about OD	*22 (9 to 35),* p=0.0009	29 (−8 to 65), p=0.12
Andrews *et al*[13]	*African American Setting*: African American churches	*Intervention:* Focused discussions about donation followed by a DVD aimed at African American concerns about donation	*18.7 (16.6 to 20.8),* p<0.0001	

*This study also reported that the intervention group was 1.7 times more likely to report being signed up to a donor register after adjustment for a range of sociodemographic and attitudinal factors (pre-test attitude scores, city, age, sex, insurance group, education and clustering by salon); however, this result was not statistically significant.
OD, organ donation.

registering, 9% of those not already on the Organ Donor Register joined on the day. The intervention was also shown to be most effective among those who had previously considered signing up but who did not know how to go about it. These community educational studies thus identify important influences on registration as both the individual's prior readiness and access to registration (table 3).

Changing knowledge

Previous research has shown that knowledge about organ donation is associated with attitudes, intention to donation and willingness to discuss organ donation intentions with family.[21–23] Among the included studies, knowledge was assessed by asking participants to indicate whether a range of statements regarding organ donation were true or false. These studies conceived knowledge as comprising five facets (1) general knowledge about donation; (2) knowledge of the relevance of donation to the ethnic minority population; (3) knowledge about the procurement and allocation of organs; (4) religious and cultural knowledge about organ donation and (5) knowledge about the financial costs of organ donation. Presentations to participants were delivered by ethnic minority transplant surgeons and donor/recipient families. Interventions tended to be one-off and commonly lasted 1 h, with immediate follow-up questionnaires administered to participants.

Two studies tested the relationship between knowledge about organ donation and willingness to become an organ donor. These studies found that significant improvements in knowledge increased the willingness among participants to state that they intended to register as a donor. Among Hispanic participants, knowledge relating to the fair allocation of organs was a significant independent predictor of willingness[24] (see table 4), while among a multiethnic sample of high school students improvements in composite knowledge scores significantly predicted a willingness to donate organs in the intervention group.[18]

The remaining two studies assessed a range of knowledge items before and after the delivery of an educational intervention. In a multiethnic sample of adults, a significant increase in knowledge was achieved for half of all knowledge items (see table 4).[25] Of particular note, African Americans who comprised 60% of the sample achieved the greatest change postintervention in relation to trust in doctors when compared to trust scores for other ethnic groups. Overall, postintervention, participants in this study reported being significantly more likely to state that they were willing to donate their own and their family's organs after death (p<0.000).[25] Unlike the aforementioned studies which focused on the lay population, Allen and Stillwater's[26] holistic interventions addressed knowledge gaps and misinformation among Alaskan Community Health aides and school children. The authors do not report details about individual aspects of knowledge addressed but report a significant increase in knowledge among both students from 58% to 95% correct (p<0.0001) and community health practitioners (p<0.0001).

Table 4 shows the number of items where a significant increase in knowledge was observed post-test. All four interventions reported that it is possible to address knowledge deficits among participants. However, no assessment was made about the extent to which gains in knowledge are maintained and whether increased willingness necessarily results in actual donor registration.

Measured shift towards greater readiness

Two educational interventions were informed by the transtheoretical model (TTM) of behaviour change[27] and measured change in an individual's 'readiness to become an organ donor'.[14 28] Both studies aimed to measure change across the five TTM stages from precontemplation to maintenance (box 2). In Fahrenwald's study, 56.9% of participants progressed to a more advanced stage post-test and none regressed, while Arriola reported that intervention participants were 1.53

Table 4 Educational interventions reporting change in knowledge about organ donation

Study	Target population	Duration and length of follow-up postintervention	Number of items with a significant improvement post-test	Percentage of items where significant increase in knowledge recorded	
Cárdenas *et al*[18]	High school students, multiethnic	60 min Immediate follow-up	12/16	75	Greater improvements in composite knowledge score predicted a willingness to donate in the intervention group *(OR 1.42, CI 1.18–1.71, p<0.001)*
Callender *et al*[25]	Multi ethnic adults	Not reported Immediate follow-up	4/8	50	Significant improvement in 4 knowledge items (1) Knowledge about higher rates of kidney disease among BME (2) Longer wait times for transplant for BME (3) less likely to believe doctors would hasten death if they knew donor status of patient (4) Less likely to state that god needs 'whole' bodies for the afterlife
Salim *et al*, USA[24]	Hispanic Adults	45–60 min	15/25	60	*Independent positive predictors of willingness to donate:* (1) Knowledge of a national matching system *(AOR 3.36, CI 1.43–7.88, p=0.005)* (2) Not perceiving that wealthy people are more likely to receive a transplant *(AOR 5.39, 2.02–14.37 p=0.0008)*
Allen and Stillwater, USA[26]	Alaskan Natives School Children	Not specified	n/r	n/r	*Scores for knowledge about donation and transplantation increased significantly pretest 58% correct vs 95% post-test p<0.001* *Students significantly more likely to state they would be a donor p=0.021*
	Community Health Aids & Practitioners (adults)	3 h presentation as part of CPD	n/r	n/r	*Significant increase in factual knowledge score p<0.001—mean knowledge scores doubled post-test* *Participants were significantly more likely to report intent to sign a donor card post-test p=0.003* *Significantly greater awareness of how and where to get information about organ donation p<0.001*

AOR, adjusted OR; n/r, Not reported.

Box 2 Prochaska and Velicer's Stages of Change[27] adapted for Organ Donation

- *Precontemplation*: Have not considered registering as an organ donor
- *Contemplation*: Considered organ donation, but not taken steps towards registration or addressing unresolved issues/concerns
- *Preparation*: Able to recognise the benefits of registration and have taken action to find out more
- *Action*: Expressed their wishes about donation by either signing the organ donor register or discussed wishes with immediate family/kin
- *Maintenance*: Occasionally reinforce statement of wishes to family members/kin

times more likely to be in a later stage of readiness than control participants.

Collaboration with members of the targeted ethnic population was undertaken to ensure the relevance and acceptability of the intervention. For Arriola *et al*,[14] this involved a specific focus on religious objections to organ donation, involvement of the church pastors and the use of a well-known gospel choir to present the intervention video, whereas Fahrenwald *et al*[28] included respected members of Native American tribes and their storytelling traditions to convey donation messages. There were significant differences in participant exposure; participants in Arriola's study were exposed to intervention materials in the home at several time points over a year (eg, through video, pamphlets and greetings cards), whereas Fahrenwald's participants received a short intervention lasting between 30 and 60 min that involved watching a video about organ donation followed by a group discussion.

Although these studies provide evidence of positive movement towards readiness to become an organ donor, sign a donor card or talk to family members about their preferences, whether those at a later stage of readiness actually signed a donor card is less clear. This issue is reflected in the UK community study where only a small proportion of participants who stated an intention to register in the future had done so at follow-up (A Warrens, personal communication, 2013).

Mass media interventions

All media interventions attempted to detect changes in the willingness or intention to join a donor register or sign a donor card.[16 29–32] However, interventions that solely utilised the mass media reported no significant change in the intention or willingness to register as an organ donor, despite focusing on a single ethnic group and undertaking formative research in the target population (see table 4 below). In contrast, a high level of success was achieved by one study[15] which innovatively combined mass media techniques with interpersonal communication. This was conducted at the vehicle licensing office, a setting where individuals are able to join a state donor registry. Harrison *et al* set out with the clear aim of focusing on members of the population categorised as *passive* positives (ie, those favourable to organ donation but not yet joined the register). To determine the effect of each component of the intervention on registrations, the campaign occurred in three stages, each lasting 3 months. The interpersonal component of the intervention accounted for the greatest increase in registrants from 444 in the previous year to 5588 post campaign. Overall, the combined effect of the intervention components increased registrations by 700% (table 5).

CONCLUSION

This review identified 18 evaluated intervention studies focusing on ethnic minorities that were educational in nature, delivered in community settings or disseminated through the mass media. All but one study was conducted in the USA, with possible implications for generalising findings to different cultural contexts and minority populations. Other limitations of the review arise from the heterogeneity of study populations, measures and outcome variables, as well as the frequent use of unvalidated measures of knowledge. Also, there were limited data on the impact of specific facets of knowledge on registration or intent to register, thus failing to identify which 'knowledge gaps' are most important to address and whether this differs between ethnic groups. It is also notable that few studies explicitly mentioned an attempt to connect with the target population during the developmental phase and access acceptability. Reporting of important contextual information relating to the interventions was also sparse. Similar limitations of a lack of rigour and theory have also been noted in a recent review of smoking-related and obesity-related health promotion interventions adapted for ethnic minority populations.[33] However, a detailed analysis of the process as well as the outcomes allowed us to identify some messages regarding effective approaches for increasing the acceptability and effectiveness of these interventions.

First, community-based educational interventions exhibited a higher level of success in terms of verified registration than those solely reliant on the mass media. Characteristics of interventions that were successful in increasing registration also tended to comprise a strong interpersonal element that focused on the particular population's concerns, delivered by members of the local community in familiar environments or in a context where individuals are required to make an immediate decision about registration. In contrast, mass media campaigns designed to promote organ donation to Hispanic and African American populations did not achieve an increase in registration. However, there was some evidence that media interventions successfully

Table 5 Effect of media campaigns on donor registration

Author Target population Language	Media Duration	Self-reported registration intention to be a donor	Pretest (%)	Post-test (%)	p Value
Frates *et al*,[29] USA Hispanic Spanish	TV and radio 3 years	*Have decided to be a donor* *Signed a donor card*	27 14	31 16	0.163 0.376
Salim *et al*,[30] USA Hispanic English and Spanish	TV and radio 1 year	*Intent to donate* (% likely or very likely)	32	30	0.488
Radosevich *et al*,[16] USA African American English	TV, radio and print media 1 year	*Donor designation on driver's licence*	33	40	0.123
Alvaro *et al*,[31] USA Hispanic Spanish	TV and radio 1 year	*Have you personally told anybody that you would like to be an organ donor (%yes)*	28.5 23.2	27.2 20.9	0.723 0.445
Hebert *et al*[32]* Chinese American Not Stated	Print media 1 year	*I do not intend to donate my organ at my death*	11	21	0.001
Harrison *et al*[15] African American English	Bill Boards in the vicinity of vehicle licensing office radio ads Face-to-face contacts with donor families	*Verified registration (counts of registrants in postcode areas with a population >80% African American)*	0.1	1.2	*0.001*

*During this campaign, a major scandal reported that a funeral home near to the intervention location had been procuring tissue from cadavers without family consent. This story was covered on national and local media.

addressed knowledge gaps and misconceptions about organ donation.[15 30 31]

Second, there are questions of whether registration always represents an appropriate outcome, given that ethnic minorities and those from socioeconomically deprived backgrounds are consistently shown to have more negative views, greater concerns and less knowledge about organ donation and transplantation compared with the general population.[34–36] Interventions should therefore consider the intermediary steps through which individuals may need to pass before the desired endpoint of registration can be achieved, and also identify clearly at the outset the stage of readiness among the intervention participants and match interventions accordingly. Moving some sections of the population from an early stage of increased knowledge to actual registration may require multiple interventions that reinforce and build on each other over a period of time. In contrast, people who are further along the pathway and have reached an action stage may only require a limited 'nudge' or 'prompt' to register as an organ donor, through interventions involving behavioural prompts, cues to action and, where possible, an immediate opportunity to register. Indeed, our recent findings from a detailed focus group study of 229 Black and South Asian participants in London found that the majority of participants possessed extremely limited knowledge about organ donation, lacking specific knowledge about how to register and the elevated need for transplant among their ethnic group.[37] While the focus group opened up a dialogue about donation and registration, it is unlikely that many participants would have been ready to sign up immediately for a variety of reasons including the need to discuss with their family, and for some people the desire to seek clarification from faith representatives. This is particularly prescient in the UK as recent data show 25% of ethnic minority families of potential donors who had formally signed the donor register refuse assent,[38] with the current practice being to respect the wishes of the family regarding donation decisions even if this does not accord with those of the patient.

Third, the review suggests that effective interventions for those in the precontemplation or contemplation phase are those undertaken in familiar community settings and delivered by appropriately trained lay individuals. In this context, lay health promoters have the benefit of an established rapport with the target population and the potential for gradual delivery of information that can be reinforced over time. Providing easy access to registration also has a significant impact on achieving increased sign-up, particularly for those at a later stage of the pathway from contemplation to behavioural outcome.

Current efforts to encourage organ donor registration in the UK have largely relied on mass media campaigns with some 'community engagement'. Although these have not been formally evaluated, there is little evidence of significant changes in overall registration rates. However, the present review suggests that these campaigns may have contributed to changes in knowledge, thus producing some shift along the pathway, although having less effect on registration practices. For the future, there is a need for rigorously conducted studies to assess the impact of specific facets of knowledge on registration or intent to register. There is also a need to develop robust intervention studies that take account of the population's readiness to sign the donor register, with approaches ranging from personal interaction and discussion with members of the lay community and facilitating a sign-up process in practice.

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