

LIFE AFTER DEATH

Supporting Organ Donation Choices for Ethnic Minority Families:

DVD Based Professional Development Pack



Enquiries to:

Professor Myfanwy Morgan
King's College London

Department of Primary Care & Public Health Sciences
Capital House, Weston Street
London SE1 3QD

E-mail: myfanwy.morgan@kcl.ac.uk

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Introduction

What is organ donation?

Organ donation is the giving of an organ to help someone in need of a transplant. This may involve the donation of a kidney by a live donor or the donation of organs by a person who has died on an Intensive Care Unit (ICU) or Accident & Emergency.

This training pack focuses on end of life care and the donation of organs from a deceased donor which accounts for two-thirds of all transplants.

Why does ethnicity matter for organ donation?

In the UK, people from Black African, Caribbean and South Asian backgrounds have higher rates of both diabetes and high blood pressure compared with the general population. This leads to rates of end stage kidney failure that are 3 to 4 times higher than the general population. Therefore, there is a much greater need for dialysis or preferably kidney transplantation for people from Black African, Caribbean and South Asian backgrounds.

However, whereas the need for organ donation from these Black African, Caribbean and South Asian communities is much higher than among the general population, donation rates are relatively low. This means that finding a successful match for blood and tissue types that are more common among minority ethnic groups is much more difficult. As a result, people from Black African, Caribbean and South Asian backgrounds spend almost twice as long on waiting lists for kidney transplantation.

Why is cross-cultural training important?

There is evidence that major influences on rates of consent to donation by bereaved relatives include families' satisfaction with end of life care and the quality of communication they receive. However achieving these goals of care and ensuring good communication and support is particularly challenging at times of considerable emotional stress and where there is a lack of awareness of the diversity of end of life practices and expectations among families from minority ethnic backgrounds.

Professional development pack

What are the aims?

The aim of the present package is to assist staff in providing individualised care that supersedes cultural difference. It therefore aims to assist staff in understanding the range of concerns and practices that they may encounter in providing end of life care and particularly in decisions regarding organ donation. It also offers strategies to best support families, specifically those from ethnic minority groups.

The actual approach for consent to organ donation will be made by a trained individual, for example, the Specialist Nurse for Organ Donation. This pack is therefore not a substitute for this specialist training. Instead it aims to assist health professionals in their confidence and skills in supporting families and providing end of life care to individuals and families from different cultural groups.

Who is it for?

It is expected that the pack may form part of the induction training for ICU nurses and training provided by Specialist Nurses for Organ Donation (SN-ODs).

How is it delivered?

The package consists of a DVD containing both a main programme and separate family scenarios, with accompanying worksheets. The package is delivered by a facilitator to a group. This provides an opportunity to broaden discussion by drawing on the participants' own experiences.

What are the learning objectives?

After completing the course the participants should:

- Know why ethnic minorities from Black African, Caribbean and South Asian backgrounds have a higher unmet need for organ transplantation.
- Be aware of the importance of the quality of end of life care and its influence on organ donation choices for families.
- Recognise the heterogeneity that occurs both within and between ethnic minority groups.
- Be aware of the five dimensions identified by DonaTE that help understand the varying responses to end of life and organ donation by people from different ethnic groups.
- Be aware of strategies for managing these situations and feel more confident in applying them to support families from different ethnic backgrounds.

Contents of training pack

The package consists of 3 components:

- A. Core DVD programme
- B. Family drama
- C. Written materials

A. Core DVD programme

This 30 min DVD begins by giving information on the numbers and diversity of ethnic groups in the UK and why there is a particularly large unmet need for kidney transplantation among people of Black African, Caribbean and South Asian backgrounds. The programme also describes issues regarding the relatively low donation rate by ethnic minorities, with bereaved ethnic minority families having a consent rate that is 50% lower than the general population, which in turn leads to difficulties in achieving an appropriate match of blood group and tissue type for kidney transplantation from a deceased donor.

The main body of the DVD is structured around five key dimensions that are informed by a large programme of community and hospital based research at King's College London (DonaTE Programme). The DonaTE dimensions are shown below:



The DVD emphasises the differences in knowledge and attitudes that may occur among families and members of a particular ethnic group in relation to each of these dimensions. It draws on the experiences of ICU doctors, nurses, doctors, and hospital chaplains as 'talking heads' to discuss ways of managing the varied situations and meeting the needs of patients and families.

These dimensions and best practices are briefly summarised below:

1. Emotional expression

People respond in different ways to acute grief; some individuals and families rarely show their grief outwardly, whereas others may engage in loud crying or wailing and sometimes show physical anguish through for example banging their head.

What you can do:

Supporting individuals and families requires being prepared for a range of reactions and allowing individual expression while ensuring safety and a lack of harm.

2. Faith, Religious and Cultural Beliefs

No faith prohibits organ donation but there are many different views and beliefs at a community level and many myths and misconceptions exist. Some people believe that donation is not permitted by their faith or are uncertain about the requirements of their faith, with such views forming a significant factor in organ donation decisions. For some families (or family members) it is also important to fulfil specific faith or cultural practices at or around the time of death.

What you can do:

Avoid making assumptions regarding individuals' faith and cultural beliefs as people of the same faith may differ in their understandings and in their personal significance of faith and culture. There is therefore a need to elicit beliefs and to provide information required to make informed choices. This may involve asking families if they would like a chaplain to visit them or their relative and also where possible facilitating particular faith based requirements.

3. Extended Family and Visitors

Both the immediate family and often other visitors wish to visit the patient in the ICU. If this involves a large number of people at any one time this may need to be managed both to retain access for key family members and to limit disruption to staff, other patients and their visitors.

What you can do:

Work with the family to ensure appropriate access to the patient for family members and other visitors. Practical arrangements may involve a rota for visitors, or using a password to access the patient. It is important to identify (rather than assume) who are the key decision-makers in relation to consent to donation and to ensure their close involvement.

4. Language and Communication

Staff and family communication needs to be clear and technical terms avoided or explained clearly to avoid misunderstandings, particularly when English may not be a first language. Good communication also requires establishing a rapport and building trust.

What you can do:

Check that key family members or decision makers understand the information they have been given. One technique is to ask them to explain to you what they understand about the patient's condition and prognosis. The development of a rapport and trust is also influenced by frequent updates, the consistency of communication (and communicator) as well as exploring and responding to fears and concerns.

5. Anxieties about Organ Donation:

Organ donation generally raises many questions and anxieties for the family and these are often exacerbated by the unfamiliar environment of the ICU and often the unanticipated situation. Key issues for relatives often relate to whether donation will delay the funeral and whether donation is compatible with treating the deceased with dignity and respect.

What you can do:

Answer the families' questions, or find another person who can, such as the Specialist Nurse for Organ Donation who has detailed knowledge regarding organ donation.

B. Family drama

These three short drama (10 mins in total) reinforce the main programme. They include a case study of a family who are informed of the death of their family member and later choices regarding organ donation are raised. The family comprises 5 members of a Pakistani Muslim family. Their experience is represented through three key scenes dipping in and out of a longer process. These illustrate the five DonaTE dimensions, provide examples of good practice and introduce the audience to processes of end of life care.



The scenes are:

Scene 1: The huddle – shows good practice for a planning conversation to break bad news that takes place between a consultant, specialist nurse and bedside nurse before approaching the family.

Scene 2: Explaining organ donation with the family – this follows the breaking of bad news and focuses on the stage of communication and the families discussion of choices regarding organ donation. This illustrates the five dimensions considered earlier in actual practice.

Scene 3: 'Breaking Bad News' – this is an additional scene that is optional for participants focusing on issues of ethnicity. The scene provides a more general example of good practice in breaking bad news and coping with the families' responses and grief reactions.

C. Worksheets (description)

Worksheet 1

Before watching the DVD, ask participants to complete Worksheet 1. This encourages participants to identify their own questions or anxieties about organ donation.

Worksheet 2

This asks participants to reflect upon the content of the case study scenarios they have watched, and to think about the families' needs and how they could support the family and individuals, their own experiences and views of good practice.

Worksheet 3

This asks participants to analyse the family case study in relation to the five DonaTE dimensions and to think about the families' concerns about organ donation.

Worksheet 4

This applies participants' learning to their own ICU and asks them to think from their experience of working in ICU of two families from different backgrounds and how those families appeared on the dimensions. It also aims to encourage participants to reflect on their unit's approach to providing end of life care to patients and supporting their next of kin.

Personal plan

At the end of the session participants are encouraged to devise a personal plan to implement some of the knowledge and skills they have learned in this development package. This focuses on identifying three intentions that they can put into place, with the overall aim of improving support for bereaved families regardless of background.

Appendix 1: Worksheets

Worksheet 1: Personal concerns and reflections

It is common for staff, like families, to have questions or anxieties about organ donation.

1) What three questions or concerns do you have about organ donation?

i)

ii)

iii)

2) In your professional role, what questions or anxieties do you have about:

i) Supporting families around end of life care and organ donation?

ii) Supporting families around end of life care and organ donation who come from backgrounds different to your own?

The Specialist Nurse for Organ Donation will be able to answer these questions or provide further information.

Worksheet 2: To follow case study scenarios

The following questions/discussion points may help to guide participants to think about pertinent issues:

- What is good about how the health professionals are talking to the family?
- What support do the family need as a whole?
- What information does the family need?
- What needs do individuals' family members have?
- How would you describe the dynamics of the family to a colleague taking over from you?
- What issues do the family raise and how could you resolve these?
- What other support can be offered to the family (e.g. faith)?

Worksheet 3: To follow case scenarios

1) Imagine you are caring for the patient and their next of kin in the scene you have just been shown. For each of the five dimensions, what is your impression of this family?

Dimensions	Your impression
Emotional expression	
Faith, religion and cultural beliefs	
Extended family and visitors	
Language and communication	
Anxieties about organ donation	

2) What concerns might the family have about organ donation, and why? How would you provide information to address their concerns and where would you find the information you need?

Worksheet 4: Final reflections

This worksheet asks participants to think about two families who reflect the local patient population. Participants are then asked to think about how the 5 dimensions may apply in their own practice.

It may help participants to begin by developing a brief background for each family e.g. relationships, age, gender, socio-economic background, faith etc. Further layers can be added, for example, information about the patient, whether any donation is likely to be Donation after Circulatory Death (DCD) or Donation after Brainstem Death (DBD).

Additional Task: the following questions can help form a discussion to help participants reflect on their and the units' approach to providing end of life care to patients and supporting their next of kin.

- What are the demographics of patients in our ICU?

- How do we identify the needs of families and patients at the end of life?

- How do we meet these needs?

- What could be improved about end of life care on our ICU for families?

- How could these improvements be implemented (costs, involvement of other staff or those outside the hospital)?

- How could we better support families?

Use the sheet on the next page to think from your experience of working in the ICU of two families from different backgrounds; for each dimension think how those families appeared on the dimension.

Worksheet 4 (continued)

Dimensions	Your unit	
	Family A:	Family B
Emotional expression		
Faith, religion and cultural beliefs		
Extended family and visitors		
Language and communication		
Anxieties about organ donation		

1) What are the specific needs of each family?

Family A:

Family B:

2) How could these families' needs be met? Think about what you or your colleagues on the ICU and beyond could do.

Family A:

Family B:

Personal Plan: Supporting organ donation choices for ethnic minority families

At the end of the session you are encouraged to devise a personal plan to implement some of the knowledge and skills that you have learned in this training package. It focuses on identifying three intentions that you can put into place with the overall aim of improving support for bereaved families regardless of background.

This has been designed to be used for you to think how better to support families and put into practice some of the knowledge and skills that you have learnt in this training package. Your personal plan does not have to be major, but try to think about personal goals that will be useful for you in your practice such as:

- I will identify some literature on the beliefs and practices of different religious groups, and ensure that these are available on the ICU for all staff.
- I will identify the contact details of local faith leaders and make a list so that staff can identify how to contact different faith leaders quickly.
- I will repeat the training in one year to refresh my memory.
- I will practice with a colleague my communication skills with bereaved families.
- I will revisit my personal plan in six months to see if I have finished it.

Personal Plan

Today's Date:..

Your intention	What problems might arise in achieving this?	How will you tackle any problems?	When will I do this?
1			
2			
3			

Appendix 2:

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