

Imperial College

OF SCIENCE, TECHNOLOGY AND MEDICINE

ATTITUDES TO ORGAN TRANSPLANTATION IN A MUSLIM INDO-ASIAN COMMUNITY IN THE UK

A thesis submitted to the University of London for the degree of Doctor of Philosophy

By

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Dedication

To all those who suffer around the World from end stage organ failure.

Acknowledgments

In the name of Allah, Most Merciful, and Most Compassionate. Praise and thanks go to Almighty Allah for; it is only with His Guidance and Mercy, this study has been accomplished.

I would like thank every person who helped me in completing this thesis. Above all, I would like to express my gratitude, sincerest, special, deep appreciation, and true thanks to my supervisor Dr Anthony Warrens, a type of person whom we rarely meet in our life, since he provided me with incredible support, excellent guidance, helpful and useful discussions and continuous encouragement, without his help and encouragement, this thesis would not have been completed this quickly. My thanks go also to my second supervisor Prof Gerry Stimson for his advice and guidance along with his research experience, which helped me to accomplish this study, before he retired from his academic post at Imperial College.

Away from the work, I am grateful to my family, especially my dear mother, who sadly passed away before I passed my PhD, I really missed her so much, also my father for his continuous prayer. Also, I would like thank my brothers and sisters back at home for their moral support and courage.

My final and most heartfelt acknowledgment must go to my wife, Banan, who provide me with her support, care, encouragement, and sacrifices from the 4th of July 2001, our weeding day, while I was doing the field study of this research. I owe this accomplishment in great part to her patience and unending support. I would like to conclude by thanking a very special person, who in just 12 months ago has changed my life forever and introduced me to joys of fatherhood, my son Fawaz.

Peace, Mercy and Blessings of Allah, the exalted, be upon them.

Abstract

The lack of organs available for transplantation is a major problem in the UK, but the immigrant Muslim Indo-Asian community, with its higher incidence of end stage renal failure, suffers more acutely. Since donation is low from within that community, the study sought to understand the attitudes to organ donation in this particular ethnic group, using an exploratory qualitative study. This approach also allowed for an assessment of the awareness of organ donation for transplantation within this community in West London. The fieldwork was divided into three stages using participant observation, focus group discussion, and in-depth individual interviews. A sample of 141 Muslim Indo-Asians, 18 years of age or older, from a variety of socio-demographic backgrounds, participated in this study (100 male, 41 female). It was found that most of the participants in this study were aware of both live and cadaveric organ donation. This information was acquired from the national media. However, most were opposed to it, for a mixture of religious and cultural reasons. This was true, despite the fact that most Islamic religious authorities have pronounced the practice acceptable under religious law. However, the participants believed that organ donation is inconsistent with Islamic beliefs. Five main themes emerged, all of which serve as important barriers to organ donation: sacredness of the body, fatalism, the role of organs as "witnesses", recipient probity, and concern about the premature declaration of death. Most of those who would consider donation stipulated that the recipient be from within their own community. There were remarkably few differences between different participants' answers. Young participants were more willing to learn about the process of organ donation than were older people. In conclusion, there is a dissonance between the facts of Islamic Law and public perceptions. Muslim scholars play a crucial role in a Muslim's life and must play an essential role in attempts to promote organ donation. Therefore, to improve organ donation rates from the community cooperate with Muslim Indo-Asian community, I suggest that the UK transplantation community cooperates with Muslim organisations and takes a role in a national awareness campaign or conference to promote discussion of information about organ transplantation amongst Muslim scholars in the UK.

Thesis description

This thesis is an exploratory qualitative approach using multi-method to explore attitudes to organ donation for transplantation in UK Muslim Indo-Asians. It is based mainly on data gathered from fieldwork in three Islamic Centres using three methods: participant observation, focus group discussion, and in-depth individual interviews. It consists of three parts.

The first part is the background to the study and consists of four chapters. The first chapter is a general introduction, which deals mainly with the problem of human organ shortage Worldwide in general and in the UK Indo-Asian community in particular. It also discusses the alternative solutions and ethical dilemmas. Chapter two is a discussion of several studies in the literature from different countries, considering public attitudes to organ donation. Since religion dominates the attitude of the participants in some studies and the influence of Islamic opinion on Muslims` attitudes to organ donation, chapter three is devoted to a discussion of Islamic Law in relation to organ donation for transplantation. Chapter four is devoted to discussing the research design and methods taking.

The second part of the thesis also consists of two chapters. Chapter five describes Muslim Indo-Asian attitudes towards organ donation for transplantation. Chapter six is devoted to describing the attitude of health care professionals toward organ donation from the Indo-Asian community. In addition, the law and policy towards transplantation in the UK is discussed. The main factors thought to make Indo-Asians lesser contributors to the organ donor pool compared to other ethnic groups in the UK and the Asian organ donation campaign is considered.

Finally, chapter seven discusses the role of public attitudes to organ donation and transplant programmes. It also considers the implications and recommendation of this study.

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Chapter 1

Shortage of human organs for transplantation

1.1 Introduction

Human organ transplantation has become an accepted and widely performed procedure all over the world. It has become as treatment of choice for many patients with end-stage organ failure.

Vorony, a Soviet surgeon, transplanted the first human-to-human kidney in 1936 and whilst the operation was technically successful, the transplanted kidney never functioned, resulting in the recipient's death two days later due to blood group incompatibility and a long ischemic time. In 1943, Peter Medawar discovered that the immune system was responsible for graft rejection (Medawar, 1944).

Further, serious attempts at organ transplantation were taking place in both North America and France during the 1950s. Disappointingly, none of these succeeded. The first successful kidney transplant took place on 23 December 1954 when the transplant team in Boston, USA, transplanted a kidney between identical twins. Thereafter, kidney transplant was performed between identical twins in Oregon, Paris and Toronto. They concluded that human kidney transplantation could be achieved when no immunological barrier existed. Their observations led to a number of very important developments in the field of transplant immunology. As a result, kidney transplant surgery expanded rapidly during the 1960s and 1970s thanks to improved immunosuppressive drugs. Later, there followed increasing success in transplantation of the heart, liver, lungs, and pancreas. The introduction of cyclosporine in the early 1980s was a highly significant advance in immunosuppressive therapy. Thereafter, organ transplantation activities expanded rapidly worldwide (Bradley & Hamilton, 2001).

However, as the demand for organs increased, the supply of cadaveric organs for transplantation did not keep pace. This chapter discusses the shortage in organs for transplantation, concentrating on kidney transplantation for a number of reasons:

- Kidney transplantation is more commonly performed than other solid organ transplants.
- Kidney transplantation was established first.
- Kidneys may be obtained through both living and cadaveric donation.

There will be discussion about those alternative solutions for organ shortage that are most frequently considered. The specific issue of organ shortage within the Indo-Asian community will be discussed in greater detail, as it is the main subject of this thesis.

I first developed an interest in investigating factors affecting the organ shortage when I was working as a transplant coordinator in the Kuwait Organ Transplant Centre. I observed that many end stage organ failure (ESOF) patients had been on the organ donor waiting list for more than a year. This may be explained by the high refusal rate for organ donation by the next of kin. Statistics show that road traffic fatalities in Kuwait are in excess of 400 per year, and those victims represent a potentially valuable source of organs to treat ESOF patients. Islamic legal opinion (*fatwa*) varies, but there is a well respected opinion that Islam supports organ donation (see Chapter Three). However, in my experience, the majority of families who refused their permission when approached were of the opinion that Islam is opposed to organ donation.

My interest was strengthened following detailed examination of previous research carried out on U.K. Indo-Asians, which appeared to indicate that Muslims are far more likely to seek religious advice before making their decision on organ donation than any other sub-group (Ahmed *et al.,* 1999; Darr & Randhawa, 1999; and Sheikh & Dhami, 2000). I hypothesized that this may have a direct correlation with the situation that I had encountered in Kuwait.

To determine the depth of the influence exerted by religious factors on severe organ shortages, I proposed to study two groups of Muslims living in different environments: the first in Kuwait City, Kuwait, and the second in West London, United Kingdom. In Kuwait, the sample was to have been taken from native Kuwaitis, influenced by an Islamic culture; whilst in West London, the Muslim Indo-Asian community, influenced also by a Western culture, was to have been studied.

I began my investigation in West London, but as I pursued my studies I identified a number of important issues within the UK Indo-Asian community, which I believe merited much more detailed study. I took the view that my time would be more usefully spent investigating these issues in much greater detail, rather than performing a necessarily more superficial analysis of a second comparative group in a different country. Thus I decided to focus my attention on the West London Muslims only. That is the main subject of this thesis.

1.2 The response to organ shortages

Continued progress in surgical techniques, intensive care facilities, organ procurement, preservation methods, and immunosuppressive drugs have all led to the successful transplantation of many vital organs. Transplantation of parts of organs or tissues including corneas, heart valves, bones, tendons, etc. is also growing very rapidly. Each year, organ transplantation saves the lives of thousands of patients who have suffered from organ failure (Chapman *et al.*, 1997). More than one million patients all over the world have received an organ transplant. Some of them have survived more than twenty-five years. Five-year survival rates for most organs are now at least 70% (Miranda & Matesanz, 1998).

The improvement in the quality of patients' lives following kidney transplantation has been well-documented (Rizvi & Naqvi, 1997). Furthermore, it is also cost-effective when compared with dialysis (*Economist*, 1996; and Evans & Kitzmann, 1998). Each patient on dialysis costs up to £35,000 a year, while transplanting a kidney costs £20,000

in the first year and £6,500 a year thereafter. Over the five years post-kidney transplant, the cost of one patient is £46,000, which is one-fourth of the costs of a patient remaining on dialysis over the same period (Ready *et al.*, 1997; UK Transplant, 2003).

On the other hand, although organ transplants have saved thousands of lives and transformed the quality-of-life of thousands more, many thousands more have died before organs became available for them. Still more remain un-transplanted on replacement therapy. The severe shortage of organ donors remains a major obstacle, preventing the full development of transplant services and imposing a severe limit to the number of patients who can benefit from this form of therapy. The increased range of indications for which transplantation is possible, coupled with the dramatic improvements in survival rates, have resulted in an ever-increasing demand for donors (Moore, 1997).

The shortage of organ donors is currently the biggest barrier to the expansion of organ transplantation activity all over the world (Hakim & Danovitch, 2001). The waiting list for all organs is increasing rapidly and adds significant morbidity and mortality to patients directly and indirectly through the increased health care costs. Each year many patients on the waiting list die without receiving organs (Pike *et al.*, 1992).

There is an ever-increasing demand for cadaveric solid organs for transplantation all over the world. The need for transplantable organs continues to far outweigh the number of organs available for transplantation through donation. Over the past decades, there have been numerous proposals to decrease the persistent shortage of transplantable human organs. In practice, increased attention has been focused on expanding the donor pool by improving organ procurement procedures (Al-khader & Shaheen, 1999).

To date, many avenues for expanding the donor pool have been explored, and many have been introduced into clinical practice. These include:

1) strategies to increase live donation,
2) strategies to increase cadaveric donor,
3) xenotransplantation and
4) other strategies.

1.2.1 Strategies to increase live donation

The King's Fund recommended in 1994 that live donation should be expanded in an attempt to increase the availability of kidneys for transplantation (New, 1994). Between 1990 and 1996, live kidney donor transplantation increased by 81% but still accounted for only 10% of all renal transplants performed in 1996 (Lumsdaine *et al.*, 1999). Nevertheless, organs obtained from live donors are perhaps the best option for many kidney transplant patients for a number of reasons: they are associated with shorter waiting times, higher survival rates, and fewer complications (New, 1994).

There are two types of live donors: "living related donors" (LRD) are donors who are genetically related to the recipient (usually parents, children or siblings) and "living unrelated donors" (LURD), or the so-called "emotionally related donors". The latter are mainly spouses and close friends. It has been determined that, despite the fact that LURDs are less well "matched" than LRDs, LURD transplants achieve a very high level of success (Terasaki, 1995). Kidney transplants from one spouse to another have a similar, if not better, success rate than transplants from parents to children, and a better success rate than perfectly matched cadaveric transplants. This suggests that the overall health of the donor may be more important than the degree of "matching" (Sankari, *et al.*, 1994; Voiculescu *et al.*, 2003).

Although the superior success rate that can be achieved by comparison with any other procedure is an important justification for it, Bollinger (2001) argued that the donor is liable to physical and psychological harm. He observed that the donor might have faced pressure to make his/her decision, and children or the mentally retarded might be taken advantage of on account of their inability to give fully informed consent. It should be added that the potential for commercialisation is "a worry".

In the UK, any potential live donation must be referred to the UK Unrelated Live Transplant Regulatory Authority (ULTRA), which was established under the Human Organ Transplant Act, 1989. In this way, it is hoped to circumvent some of the problems associated with live donation. However, between 2001 and 2002, only 135 cases were approved by ULTRA (Report 1999–2002). Live donation clearly does not yet offer enough of a solution to the problem of organ shortage.

Other factors that are being considered to improve further the number of live donors available include allowing altruistic donation (to an unnamed recipient), "buddy" donation (between, for example, individuals from different husband-wife pairs where the spouses are incompatible with each other), and by allowing the reimbursement of expenses.

1.2.2 Strategies to increase cadaveric donor

Approximately two out of every three transplanted kidneys come from people whose organs were donated at the time of death. This is cadaveric donation. These donors can be divided into two types: a "heart beating" donor (HBD) is a person who has died while on a life-support system and whose death is established using brainstem death criteria; a "non-heart beating" donor (NHBD) is a patient whose cardiopulmonary function ceases before his/her organs have been retrieved. An NHBD is still able to act as a donor if his/her organs can be removed immediately on death (Kootstra *et al.*, 1995).

Non-heart beating donation was first performed at the University Hospital in Maastrich in 1980 (Booster *et al.*, 1993). A number of transplant units in the UK are developing interests in this approach. In Western Europe and the USA, this type of donor accounts for 20–40% of all kidney donors (Treska & Hasman, 2001). Koffman and Gambaro (2003) argued that the use of NHBD has consistently increased the number of available kidneys and has no effect on the number of heart beating donations.

However, this procedure demands a lot of effort on the part of the retrieval team who must be able to attend the appropriate department within a few minutes. Nicholson (1996) argued that a successful NHBD programme requires good co-operation between the transplant team and the staff of other departments, such as Accident and Emergency and Coronary Care Units.

The main problem with NHBD is the inevitable period of warm ischemia, which may adversely affect tissue viability and graft function after transplantation. Although warm ischemic injury *per se* does not preclude successful transplantation, reduced tolerance to subsequent cold storage of organs from NHBDs has been shown when compared with grafts from heart-beating donors (Muiesan, 2003).

Despite a higher level of delayed graft function, the results from non-heart beating renal transplantation are "good", with long-term function comparable with cadaveric organs. Hence, the transplantation of selected kidneys procured from non-heart beating donors should be promoted as a response to organ shortage. But it must be borne in mind that delayed graft function is more frequent in non-heart beating donors (Schon *et al.*, 2001).

In spite of this, ethical issues still constitute the main hurdle to the wider acceptance of NHBD. These include questions regarding the cultural perspective of death, family consent, and the use of procedures or medications that subordinate the interest of the patient to the goal of organ preservation, which is only in the interest of the ultimate recipient. Perhaps the greatest ethical question with NHBDs is how precisely to define the moment of cessation of life (Bollinger, 2001).

1.2.3 Xenotransplantation

The term "xenotransplantation" has recently become a subject of interest in the field of organ transplantation. In this context, this means the transplantation of animal parts or organs to humans (Melo *et al.*, 2001). Some predict that within a decade, the possibility of the development of genetically engineered organs will allow us to produce tailor-made organs to for human use. Millions of pounds have already been invested in research into pigs as potential donors. However, this procedure raises many questions of medical ethics and animal rights (Brouard *et al.*, 2001).

There are also numerous barriers to xenotransplantation, including aggressive graft rejection, potential xenozoonosis, and physiological incompatibilities. Furthermore, the level of immunosuppression drugs may have to higher due to the increased risk of rejection (Bigam *et al.*, 1999). Although the use of animals as an alternative source is still being considered, so many problems remain unresolved that xenotransplantation cannot yet be put forth as a practical solution.

The United Kingdom Xenotransplantation Interim Regulatory Authority (UKXIRA) was set up to regulate the development and implementation of xenotransplantation in the UK. Ferran and Bach (2001) stressed that although tremendous progress that has been made over recent years, caution is needed before proceeding to clinical implementation.

1.2.4 Other strategies

At an even earlier stage of scientific development than xenotransplantation, several other approaches are being studied. Foremost among these is the tissue engineering approach. This aims to learn how to develop replacement organs *in vitro* (or *in vivo*) from stem cells (Hakim, 1997).

1.3 Continental Europe

Although there has been a dramatic growth in the number of the organ procurement organisations, transplant programs, and new initiatives related to solving the organ shortage, as well as in the development of protocols dealing with the logistics of facilitating organ and tissue recovery, in European countries at the moment there are nearly 40,000 patients waiting for a kidney, whilst the number of cadaveric donors remains stable at around 5,000 each year (Van der Vliet *et al.*, 1984, and Miranda &. Matesanz, 1998).

There is significant variability in the number of organs retrieved per million population in different European countries. This is demonstrated in Figure 1.3.1. One possible explanation of this variability may lie in the different frameworks used to obtain cadaveric organs. There are essentially three such frameworks followed in Europe to obtain consent for the removal of organs from a dead individual: 1) Presumed consent: in the absence of recorded prior objection from the deceased, organs may be removed (Austria, Czech Republic, Finland, Hungary, Poland, Portugal, Sweden, and the Slovak Republic); 2) Contemporaneous active consent: removal of organs requires the express consent of the deceased or the family members (Denmark, Germany, Ireland, Netherlands and the United Kingdom); 3) Some countries have developed a "middle way" which is theoretically presumed consent but practically informed consent (Belgium, France, Greece, Italy, Luxembourg and Spain). I shall now explain this approach in reference to the Spanish system.

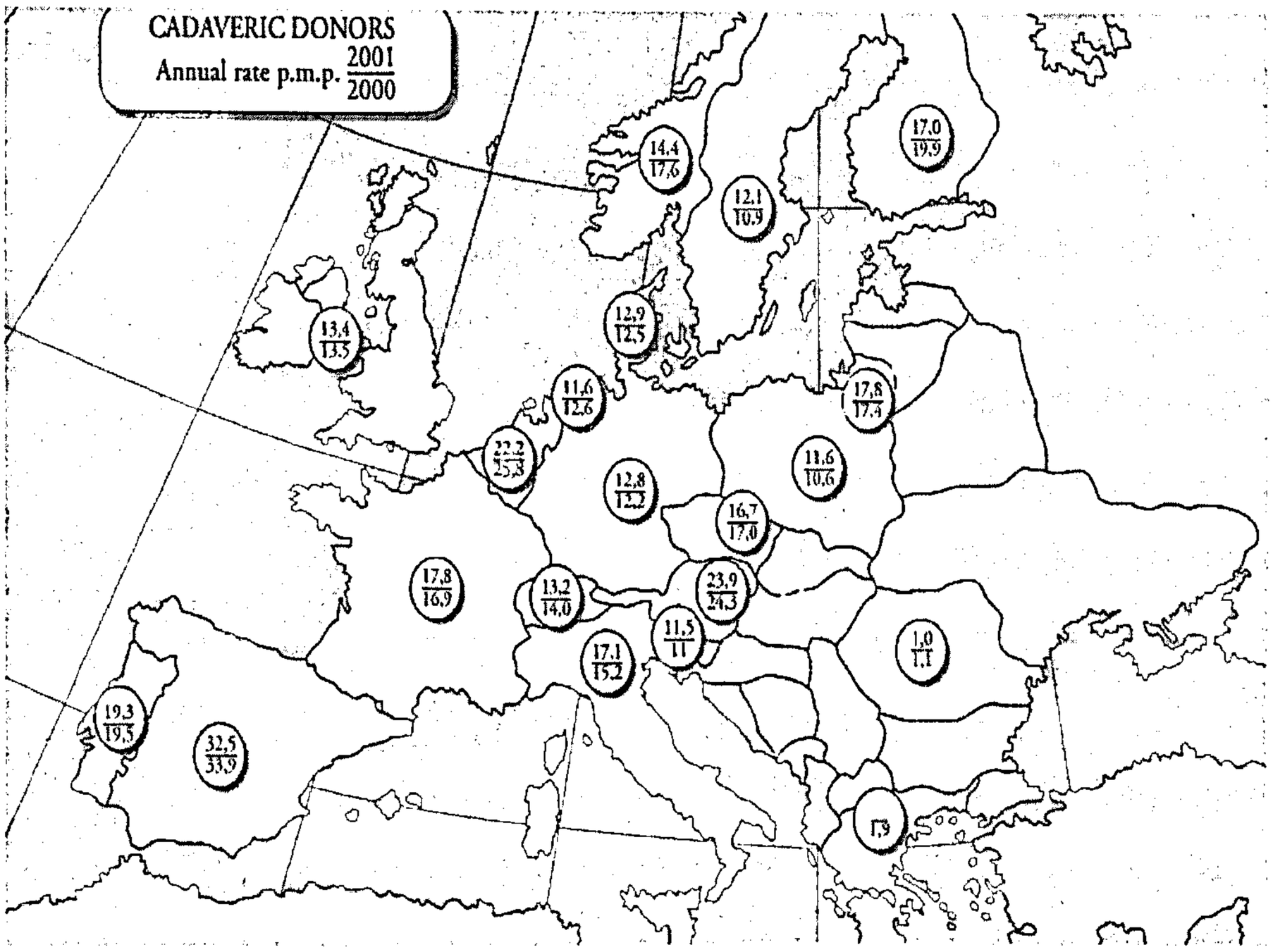


Figure 1.3.1 The aggregate number of kidney transplant from cadaveric donors per million population in European countries (ETCO, 2001)

As we can see from Figure 1.3.1, Spain is in the forefront of European countries in cadaveric donation. Indeed, they lead the world in organ donation and stand in sharp contrast to the USA. Spain is the only example in the world of continuous improvement in cadaveric organ donation in a large country over a ten-year period (Bosch, 1998).

In respond to organ shortage, the Spanish Department of Health established in 1989 a special authority to enhance organ donation and transplantation, called the Organización Nacional de Transplant (ONT). They believed that the development of any transplant programme needs to empower the public and generate an effective professional network. Thus, they funded a campaign costing around five million Dollars. In addition, they mainly appointed physicians as transplant coordinators. In addition, ITU specialist worked part-time on with the ONT. The Spanish experience in organ transplant has been remarkable. Although they have adopted a presumed consent approach, such that any person is a potential donor, they have the highest donation rate in the World (Miranda *et al.*, 1999). The average rate of donation increased from 14 donors per million population

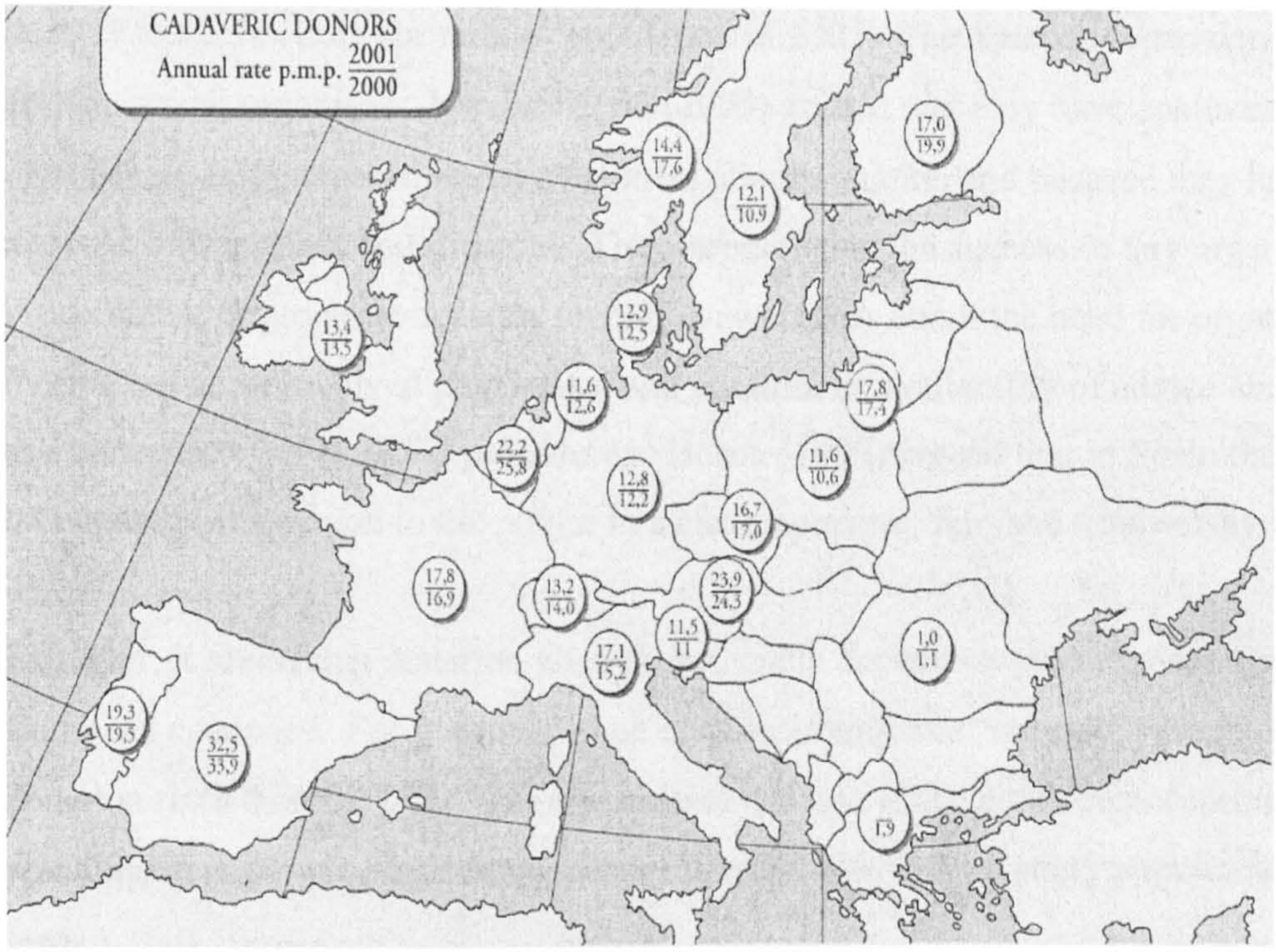


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in 1989 to 32.5 donors per million population in 2001. The Spanish organ donation system is well organised. Miranda *et al.* (1999) argued that they have achieved these rates because of increased social awareness about donation and because they have a good network of transplant coordinators. They stressed that the success of any organ procurement programme depends on public awareness about the need for organ donors, motivation of all involved physicians, and continuous availability of advice and assistance in organ retrieval procedures. Bosch (1999) argued that in Spain they have transmitted information to the public in a clear, concrete, fair, and trustworthy fashion.

However, it seems that donation rates do not solely depend on procurement systems in European countries. For instance, some countries that have "opt-out" systems have lower donation rates than the UK. This emphasises the role of the public in accepting or rejecting an organ procurement system or it might also reflect safety policies, like traffic laws.

1.4 The United Kingdom

In the UK, the number of patients on transplantation waiting lists has increased from 3,200 in 1990 to 6,983 by the end of 2000. The number of organs available for cadaveric solid organ transplantation declined from 1,793 in 1995 to 1,487 in 2000. Fewer than 2,600 transplants are carried out in the UK each year and more than 6,500 people are waiting for an organ transplant that could save or dramatically improve their lives (UK Transplant, 2003). There is a desperate need for more donors, as nearly 400 people died while waiting for a transplant in 2002. One study indicated that one in five patients waiting for a donor organ in the UK dies while waiting (Kmietowicz, 1999).

Figure 1.4.1 shows the rising numbers of people in need of transplantation set against the decline in cadaveric organ donations. The reasons for the decline in donor numbers are not clear.

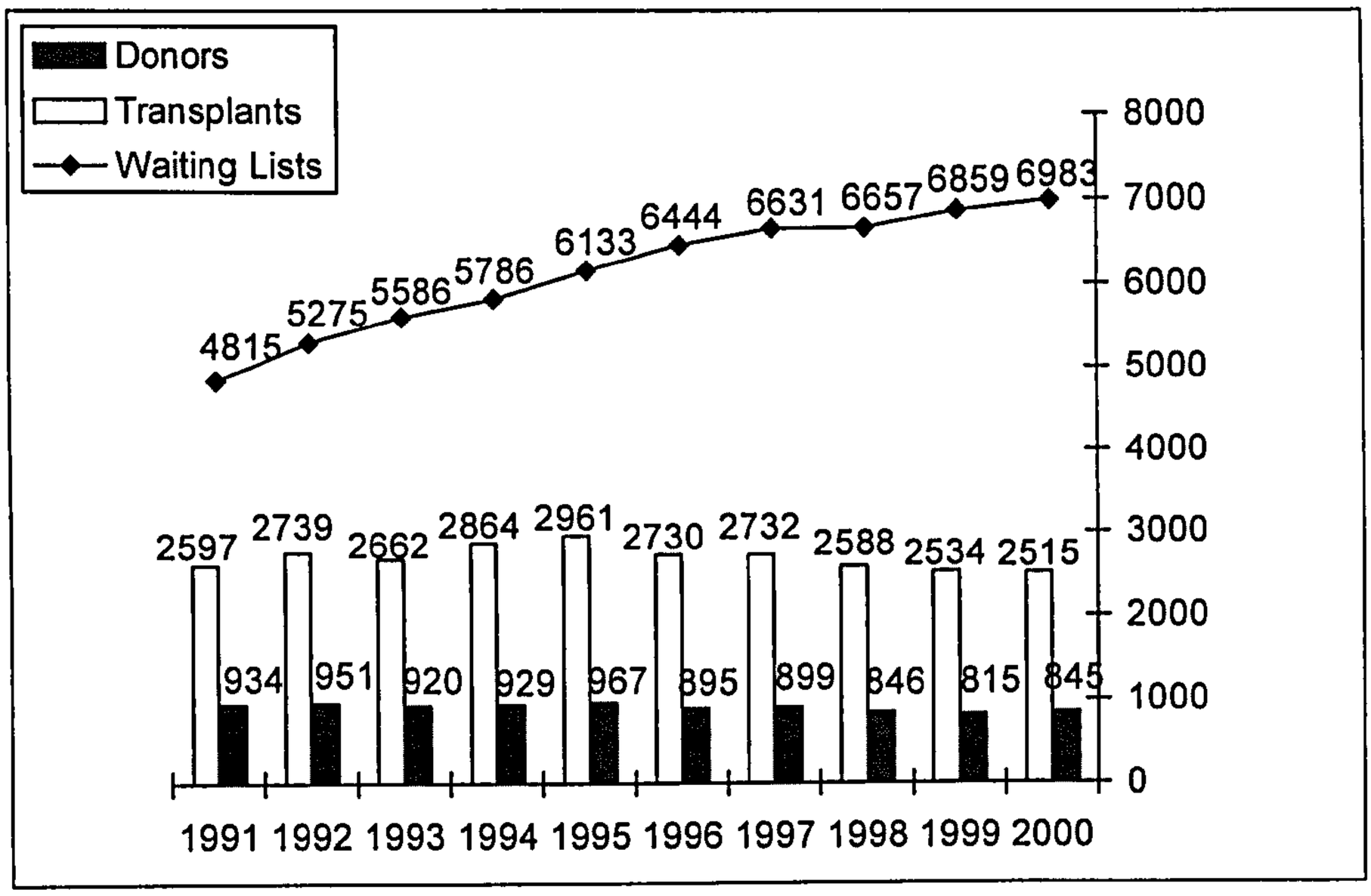


Figure 1.4.1 UK Transplant activities from 1991 to 2000 (UK Transplant, 2001).

In addition, patients with end-stage organ failure have to wait a very long time before they get the transplant they need.

1.4.1 Organ shortage among Indo-Asians

This shortage of organs is even more acute in Asian ethnic groups, especially those who originate from the Indian subcontinent (Indo-Asians) and have lived in the UK since the 1950s or before. The rate of organ donation among the Indo-Asian community is much lower than that of other sections of the British population (Ball *et al.*, 2001). Donnelly *et al.* (1992) noted that organ donation among Indo-Asians is rare because people from this community are less likely to consent to organ donation for transplantation. This finding was supported by Clark and Coats (1993), who believed that there is a reduced supply of healthy organs suitable for transplantation.

During 2000, only 2% of cadaveric solid organ donors in the UK were Asian. While the number of kidneys transplanted into Indo-Asian recipients in the UK between 1995 and 1999 was 284 out of more than 6,000 (4.1%). The percentage of Asian patients recorded as active on the solid organ waiting list in the UK on 9th April 2001, was 15% for a kidney (UK Transplant, personal communication).

These data fail to take into account the fact that Indo-Asians have a higher incidence of end-stage kidney failure (ESRF) compared with other ethnic groups in the UK (Lightstone *et al.*, 1995; Ready, 1997). Mather and Keen (1985) warned in the 1980s that the prevalence of diabetes among Indo-Asians in Southall would lead to increase patients with ESRF. Koppiker *et al.* (1998) found that the incidence of diabetes is higher in the Indo-Asian community in comparison with Caucasians. Also, type II diabetes mellitus has a high prevalence in the Indo-Asian population as shown by Davies *et al.* (1999). Lip *et al.* (1998) also found that Indo-Asians were at greater risk of ischemic heart disease.

Ready (1998) argued that the reason behind the low rate of transplantation into Indo-Asian recipients appears to be related to differences between the distribution of ABO blood groups and HLA tissue types in the UK Caucasian and Indo-Asian communities. He also stressed that the growing number of Indo-Asian patients on dialysis will have "major economic implications". He stated that around two hundred Indo-Asian patients remain on dialysis, costing around eight million pound every year. In some regions of the UK, more than 25% of people on kidney transplant waiting lists are Indo-Asian (Donnelly *et al.*, 1992; Exley *et al.*, 1996).

This problem is more pronounced in Indo-Asians living in the Greater London area. At the Hammersmith and Charing Cross Hospitals, in West London, there were 232 kidney patients on the kidney transplant waiting list, of whom 29% are Indo-Asian (Hammersmith Hospital NHS Trust, 1999). Ball *et al.* (2001) showed that the annual incidence of end-stage kidney failure among the Indo-Asian community served by St Mary's Hospital in London is 221 per million population.

Despite efforts to establish and maintain successful transplantation programmes, the number of kidneys that have been transplanted into Indo-Asians in the last decade has actually declined. These efforts to increase the number of organ donors are unlikely to succeed and this leaves a change in public attitude as the only solution.

For any organ transplantation programme, there are three inter-related elements: a recipient, a donor, and the health care professional team. However, it is clear that organ transplant activities also require the involvement of society in general (Quah, 1992).

Organ transplantation is one area of modern medicine in which consideration of human values and culture are as important as work on the specific medical aspects (Thomas *et al.,* 1992). Thus, the generation of a positive public attitude to organ donation for transplantation should be considered an important part of any transplantation programme.

Despite many campaigns conducted in the UK, the National Kidney Federation showed that only 18% of British people carry a donor card (Anonymous, 1999). Changing the organ shortage in the UK will depend largely on public attitudes. That is the subject of this thesis.

1.4.2 The context of organ donation in the UK

The issue of organ shortage is a concern to both the Department of Health (DoH) and healthcare professionals within the National Health Service (NHS). In 1991 to address a range of support functions for transplantation, the DoH decided to establish a special health authority; the United Kingdom Transplant Support Service Authority (UKTSSA). However, following the publication of "The Review of the UKTSSA" in February 2000, the Government concluded that transplantation in the UK was under-performing in comparison to other European countries. It was clear that the UKTSSA did not command the necessary authority to undertake additional functions, and it was recommended that they should be given more responsibility for maximizing organ donation across the country. To ensure prompt implementation, new regulations would be required in the

areas of organ procurement, transplant co-ordination, regulation, policy development, clinical audit, and service organization (Department of Health, 2000a).

Thus, in July 2000, UK Transplant was established with new responsibilities for all aspects of the donation matching and allocation of solid organs and corneas for transplantation across all of the countries in the UK. Objectives included: raising public awareness of the importance of organ donation; acting as a central point for information on transplant matters; maintaining the National Organ Donor Register; contributing to the development of performance indicators, standards and protocols which guide the work of organ donation and transplantation" (UK Transplant, 2001).

UK Transplant mounted campaigns to encourage people to donate their organs, but unfortunately their efforts were compromised at the outset, when in July 1999 it was reported that a transplant team had agreed to a family's request that the organ of a dead relative be given to a white person only (Beecham, 2000). The influence of racism in organ donation was clearly a concern to the media and public at large, but worse was to come.

Later that same year came the revelation that children's organs had been removed for research purposes without parental consent at Alder Hey Hospital in Liverpool. A pathologist at the hospital, described as the largest children's hospital in Britain, admitted that, for the past seven years, organs had been routinely removed for research purposes. When the parents of deceased children treated at Alder Hey and other hospitals confirmed that they had never given, nor indeed had been asked to give, consent for their children's organs to be used for research purposes, public confidence was under-mined (Bauchner & Vinci, 2001).

The British government reacted swiftly to contain the situation by making it clear to the public that there was a marked difference between retaining organs for research and retrieving organs for transplantation. The DoH stated that the aim was to distinguish between organ donations and organs being retained after a post mortem. At the same

time, NHS hospitals and staff received guidance reminding them that organ donation offered under racist conditions must be refused under the Race Relation Act 1976 (Department of Health, 2000b). Furthermore, in February 2001, the DoH released new guidelines emphasising the role of the deceased's family in giving consent to any organ retention (Department of Health, 2001).

There was great anxiety that the adverse publicity would have a damaging affect on organ donation as people's trust in the NHS declined. Fortunately, this was not the case and, following the conditional organ donation and organ retention inquiry, there was actually an increase in organ donation. It is possible that the publicity surrounding the two issues may have indirectly contributed to the increase in donors.

Certainly, in February 2001 (immediately after the findings of the inquiry were published) significant increases were seen in the number of registrations to the Organ Donor Registry (ODR), and within six months, the number of people who had joined the register had risen by a further 100,000 compared to the same period the previous year (UK Transplant, 2003). In addition, organ donation was stabilised to around 850 organ donors during the period 2000:2003 (Table 1.4.1).

The Transplant Authority (UKTSSA or UK Transplant), with the support from the DoH, media and commercial organisations, launched several campaigns to encourage public awareness of the need for organ donation and the desirability of prospective donors informing their relatives in advance of their desire to be an organ donor. They believed that widespread public support for organ donation would be the key to the successful development of the transplant programme.

The need to raise awareness within ethnic minorities, particularly Black and Indo Asians, of the issue of organ donation was also identified. Statistically the donation rates from these two groups were relatively low, whilst their need for transplants was increasing. Consequently in 1999, the Government launched the first South Asian community campaign and this was followed by a three-year strategy to raise awareness of the

growing number of Indo-Asian patients currently on the waiting list in order to encourage members of the community to place themselves on an organ donor register (Department of Health, 1999a).

In addition, the first organ donation campaign specifically aimed at raising the Afro-Caribbean community's awareness of the need for organ donation was launched in March 2002, focussing on the fact that black people are three times as likely to develop kidney failure and that under one per cent of organ donors are black (Department of Health, 2002a).

Interestingly, it appears that UK Transplant was effective in its efforts because on 2nd December 2002 the DoH announced that the Organ Donor Registry had reached "a historic milestone" with the registration of its ten millionth person. During 2000, there were approximately eight million people registered as organ donors. As a consequence a new target to double the numbers on the register to sixteen million by 2010 was set (Department of Health, 2002b).

As mentioned previously in this chapter, there are two distinct frameworks that are followed in Europe to obtain consent for the removal of organs from a dead individual: "opt-in" and "opt-out". The would of organ donation operating in the UK, known as "opting-in", means that organs can only be removed with the explicit prior consent of the person himself or with the approval of the next of kin after death. .

There are three ways in which people can specify their wish to have their organs donated following their death:

a) by signing an Organ Donor Card,

b) by placing an "organ donor" sticker or checking a box on the back of their driver's licence, or

c) by registering the form with their GP.

Unfortunately, it seems that the vast majority of British citizens do not take any of these steps. Indeed, recent data from UK Transplant shows that only 18% of the total population are carries an organ donor card (Anonymous, 1999), and only sixteen percent of the total in London (UK Transplant, 2003).

However, under the current system, anyone desiring to donate organs following their death may find their wishes ignored unless they have made their intentions explicitly clear to their family. Clearly, the relatives of a prospective organ donor are the most important link in maintaining organ availability, as they must give their consent for organ retrieval. Indeed, in some cases relatives have overridden the wishes of the deceased by refusing permission for the removal of organs.

UK Transplant has developed a high profile and is seen as part of mainstream health service provision. The strategic context of the authority's work has evolved in other ways as well: impending legislation will offer opportunities to improve donation rates further and its recently published policy document places great emphasis on increasing organ transplant rates (UK Transplant, 2003). This professional and non-governmental organisation seeks to improve organ donation in response to the increasing gap between those in need of an organ transplant and the number of organs actually transplanted and thereby strengthen the transplantation program.

On 13th June 2000, the British Medical Association (BMA) launched a major public campaign involving more than twenty non-governmental organisations who joined together to form "The Transplant Partnership" with the specific aims of stimulating wide-ranging debate amongst health professionals, policy makers and the general public at large, and to campaign for a radical review of the organ donation system in the UK and the support of the Government at different levels (British Medical Association, 2000).

The BMA took the initiative during the campaign and published its paper "Organ donation in the 21st Century" intended to stimulate debate amongst health care professionals, policy makers, and the general public. The paper concentrated on the issues and problems of organ donation and transplantation together with the urgent need to review the system in order to develop a legal and practical framework.

The authors showed great courage when they called for a change to the current donation system operating in the UK in favour of a system applied in some European countries, known "opt-out" or "presumed consent". This would operate on the premise that every person living in the UK would be deemed to have given their consent to organ donation unless they had specifically recorded in writing their unwillingness (Organ Donation in the 21st Century, 2000).

The DoH stated that any suggestion aimed at improving the organ donation rate would be considered. However, regular surveys showed that only 25% of the population were in favour of an "opt-out" scheme and the system could not be changed without public approval. A survey conducted by the DoH on a sample of 1,757 participants aimed to measure the extent of public support for the current system versus the "opt-out" system. The results of the survey revealed that fifty per cent of the participants were in favour of the current system, compared to twenty-eight per cent in favour of "opt-out" system (Department of Health, 1999a).

Furthermore, one of the reasons why "opt-out" is less practicable is that, because of the threat of HIV and other infections, a full medical history has to be taken and relatives have to be interviewed. Consequently, if, during questioning, relatives object, organs are not retrieved, whatever the legal position, for fear of adverse publicity. The only convincing evidence of an effective system to improve organ donation rates was obtained when designated staff in hospitals were assigned to ascertain the wishes of dying patients (Department of Health, 2000).

With the implementation of the new policies for hospitals in the UK, and the continuing campaign to educate the general public, it is anticipated that donors will continue to increase as more families are offered the option and subsequently agree to donation. However, some of the changes proposed in the BMA's paper are likely to be considered controversial and will need to be debated thoroughly before being implemented. For example, it should be considered that if presumed consent applied then the next of kin would have no input regarding their loved one's remains. In the context of the current study, this runs the risk of offending those of Indo-Asian descent, who place a high value on family ties.

The year 2003 witnessed a major development in the organ donation and transplantation system in the UK. On the 7th July 2003, whilst I was writing the final draft of this thesis, the DoH launched a new iniative called "Saving Lives, Valuing Donors - a Transplant Framework for England". The document outlined the Government's future plans for transplantation in England (Scotland and Wales already have transplant framework documents in place).

The main aim of the framework is to increase the transplant rate through "developing a transplant service that respects the dignity of donors and is sensitive to the needs of families and friends and transplant recipients that will ensure at least 16 million people are registered on the NHS Organ Donor Register by 2010" (UK Transplant, 2003).

What I found particularly interesting about this Framework is that for the first time the issue of cultural and religious differences between UK residents was raised. It stated that "Attitudes to organ donation differ greatly between different religious and cultural groups; health professionals need to be aware of these factors and respond to them with sensitivity" (Ethical practice, paragraph 1.8).

In recent years the DoH has become increasingly aware of cultural and religious needs, particularly in relation to organ donation. In March 2000 a national conference called "Organ donation and Transplantation: the multi-faith perspective," was assembled in Bradford specifically for the purpose of discussing the views held by the major religions in the UK. Furthermore, in 2003, UK Transplant printed a pamphlet containing religious guidance to organ donation from the main religious groups in the UK (Buddhism, Christianity, Judaism, Hinduism, Islam, and Sikhism).

1.5 Conclusion

Although there are multiple strategies being implemented to increase the number of human organs for transplantation, there is still a severe organ shortage Worldwide. As in many areas, public attitudes play a crucial role in this issue. In the next chapter, I will review literature on attitudes toward organ donation for transplantation.

Chapter 2

Public attitudes to organ transplantation

2.1 Introduction

This chapter reviews the literature dealing with public attitudes toward organ transplantation and relates it to this study. A systematic review of the literature published from 1970 to 2001 was conducted by a search of online databases, retrieved through the CHEST OVID BIOMEDICAL SERVICE, ATHENS. It comprises the following data sets: BIDS, WEB OF SCIENCE, BIOMED, CINAHL, NISS, AND NESLI. A manual review of references cited in each relevant publication was performed. The search included all languages and the keywords used were "organ donation", "transplantation", "public attitude", "public opinion", "Indo-Asian", "Islam", "Muslim", "ethnic minority", "United Kingdom", "organ failure", and "cost-effectiveness".

Over the past two decades, various studies from different countries in the World have considered public attitudes to organ donation for transplantation. Most of these studies have taken place in the United States of America (USA). This makes it hard to extrapolate these findings to the UK or any other country, on account of cultural and health system differences. Public attitudes to organ donation should really be analysed separately in each country. Nevertheless, there are factors that are common to different countries. Accordingly, I shall begin be reviewing the Worldwide literature on the subject.

A few studies have attempted to address the attitudes to organ donation of Indo-Asians in the UK. In the second part of this chapter, I shall consider those in more detail.

2.2 The significance of "attitude"

Before discussing factors influencing public attitudes, it is appropriate briefly to address what is meant by the term, "attitude"? There are various definitions of attitude. Fishbein and Allport (1967, P.8) defined attitude as:

> *A mental and neural state of readiness organised through experience, exerting a directive or dynamic influence upon the individual's response to all objects and situations with which it is related.*

The above definition suggests that the main characteristics of attitude are: mental state, readiness to respond, organisation, experience, and object. This definition makes several points. It might be argued that these five concepts exert a directive influence on individual's attitude. According to Rajecki (1982), an attitude may be viewed as a psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour toward another person or an object.

On the other hand, the direction of the attitude is determined by the amount of information acquired by the individual. This implies that an individual either shows a degree of favour to an object, and is deemed to have a positive attitude towards it, or expresses disfavour and is considered to have a negative attitude (Abelson, 1972).

However, Oppenheim (1992) argued that although one's attitude is a wider compound of values, beliefs, and feelings of an individual, it is linked with components of other attitudes and with the deeper level of value systems within a person. It can also be argued that an individual's attitude is influenced in a major way by society. According to Stuart (1977), social attitude in fact is the sum of individual attitudes directed toward social objects. He stressed that custom and environment all play an importance role in shaping social behaviour. I can conclude that attitude is a learned response that is consistently favourable or unfavourable towards a given issue.

The study of an attitude is important because its helps to explain the consistency of an individual's behaviour toward an issue in a society, since a single attitude may underlie many different action (Jones, 1975). Numerous studies have attempted to measure public attitudes toward many different aspects of life.

2.3 Worldwide studies

Differences can be seen in the findings of studies exploring attitudes to organ donation and willingness to consider personal donation. Most of the studies conducted during the 1980s were interested in investigating the willingness of the public to consider organ donation. In contrast, the social components and individual beliefs underlying that willingness (or otherwise) were given more attention in the studies of the 1990s. Furthermore, many of the studies of the 1990s investigated the attitudes of minorities and subsets of those who professed a religious belief system. These studies are summarized in Table 2.2.1.

In general, most of the studies reviewed reflected an overwhelmingly positive attitude by the public to organ donation. In addition, it was evident that the public were aware of and generally knowledgeable about the subject. However, the percentage of who people had signed an organ donor card ranged from less than two per cent (Gabel & Lindsborg, 1988) to just over twenty per cent of the total respondents (Manninen & Evans, 1985; and Aswad *et al.,* 1992).

In some studies, respondents who aware of organ donation were asked to identify their source of information. The most common sources from which people gained information about organ donation were television, newspapers, and radio which demonstrated the importance role of mass media in public information (Manninen & Evans, 1985; Corlett, 1985; Kyriakides *et al.,* 1993; and Roels *et al.,* 1997). These studies indicate that the mass media have, at least historically, been more important sources of information than personal communication. This was supported by the study of Moray *et al.* (1999), who

reported a jump in donation rate following the publicity of television coverage of issues related to organ donation and transplantation.

AUTHORS	COUNTRY	SAMPLE SIZE	METHODS
Manninen & Evans (1985)	USA	2,056	Telephone survey
Corlett (1985)	Canada	60	Six focus groups
Gabel & Lindskoug (1988)	Sweden	969	Questionnaire
Johnson *et al.* (1988)	USA	60	Structured interview
Wakeford & Stepney (1989)	UK	1,471	Structured interview
Dominguez *et al.* (1991)	Puerto Rico	300	Mail questionnaire
Alfaqih (1991)	Saudi Arabia	850	Questionnaire
Martinez *et al.* (1995)	Spain	1,288	Questionnaire
Martinez *et al.* (1991)	Chile	421	Structured interview
Bilgel *et al.* (1991)	Turkey	210	Structured interview
Davidson & Deveny (1991)	USA	232	Questionnaire
Pike *et al.* (1992)	South Africa	1,299	Questionnaire
Aswad *et al.* (1992)	Saudi Arabia	4,680	Questionnaire
Gallup (1993)	USA	6,127	Questionnaire
Schutt & Schroeder (1993)	Germany	288	Questionnaire
Kyriakides *et al.* (1993)	Cyprus	910	Structured interview
Sanner (1994)	Sweden	149	Questionnaire
Abbud-Filho *et al.* (1995)	Brazil	730	Questionnaire
Rene *et al.* (1995)	USA	158	Structured interview
Liu *et al.* (1997)	China	3,012	Questionnaire
Roels *et al.* (1997)	Belgium	1,306	Mail Questionnaire
Joun *et al.* (1997)	USA	101	Questionnaire
Toronyi *et al.* (1998)	Hungary	66	Structured interview
Rachmani *et al.* (2000)	Israel	1,338	Structured interview

Table 2.2.1. Summary of studies conducted Worldwide to investigate attitudes to organ donation

Attitudes to organ donation and transplantation vary according to the socio-demographic characteristics of the respondents. More positive attitudes toward personal donation or donation by a relative correlated best with younger, white and male respondents. Similarly, respondents with higher education and higher income reported a greater willingness to donate organs (Manninen & Evans, 1985; Corlett, 1985; Johnson *et al.*, 1988; Dominguez *et al.*, 1991; Martinez, *et al.*, 1991).

This trend was not seen in all studies, however, Kyriakides *et al.* (1993) in their work indicated that respondents with a college education were less willing to donate, compared with less well-educated persons. Dominguez *et al.* (1992) concluded that residence, place of work, and having a relative or friend on dialysis were factors that did not influence attitudes. Also, they found that older persons had a more positive attitude toward organ donation.

Public trust in doctors plays a crucial role in people's attitude to organ donation. The study of Wakeford and Stepney (1989) found that, despite sixty-three per cent of the respondents being sure that doctors would never approve the removal of organs unless they were certain the patient was dead, thirty per cent had anxieties that doctors might sometimes be pressurised to do so. Nevertheless, fifty-three per cent of respondents stated that they would trust doctors completely. However, twenty-eight per cent had a "tiny doubt" and twelve per cent were not sure but had major worries. Furthermore, twenty-five per cent stated that they would like to discuss the issue of organ donation with their GP, while thirty-five per cent regarded it as none of the GP's business.

Cultural background and religious affiliation exerted a significant influence upon the public's attitudes to donate their organs. Marshall and Daar (1998) argued that, although organ transplant surgical techniques are almost the same, differences in social customs and religious views regarding the body influenced the organ donation rate and transplantation activities. They stressed that there is a relationship between organ transplantation and cultural understanding of the social context regard the meaning of death. They found that ethnic minorities in a society practically always have poor donation rate due to cultural and religious factors.

As indicated in chapter one, ethnic minority groups are over represented in both numbers and length of waiting time on transplant lists in UK. Several studies have been undertaken to determine why more members of the ethnic minorities' are not organ donors. These have provided insight into the cultural and religious beliefs that represent major barriers in the decision to donate. Some studies found common reasons for the

reluctance to donate organs, including a lack of transplant awareness and a distrust of the health care professional. A fear of premature declaration of death following the signing of an organ donor card was also identified (Hall *et al.,* 1991; Dominguez *et al.,* 1991; Davidson & Devney, 1991; Rene *et al.,* 1995; Rubens *et al.,* 1996; First, 1997; Schutte & Kappel, 1997; Joun *et al.,* 1997; Kobrun & Modiba, 1998; Yuen *et al.,* 1998; Guadagnoli *et al.,* 1999; Siminoff & Arnold, 1999).

In addition to these factors, Toledo-Pereyra (1992) identified economic constraints, lower rates of insurance coverage, and language inaccessibility as potential barriers to organ donation in ethnic minority groups.

Various factors inform individuals' decisions to donate organs for transplantation. Radecki and Jaccard (1997) stressed that an individual's beliefs about organ donation is considered as fundamental to his/her decision. They identified five broad areas affecting organ donation: religion, culture, knowledge, altruism, and normative behaviour. However, they believed that religion and culture were the predominant barriers to organ donation.

In practice, it is common for the health care professional to require a relative's consent before removing organs for transplantation. Hence, the relative's decision potentially exerts a large impact on the consent decision. It has been found that the willingness of the individual him/herself alone is insufficient and is influenced by his/her relatives. In practice, the decision to give consent rests almost exclusively with the relative (Perkins, 1987).

Thus, Radecki and Jaccard (1997) found that consent decisions are mainly guided by the relative's cultural and religious stance on organ donation. In the study conducted by Gabel and Lindskoug (1988) in Sweden, respondents were asked if they would donate their relative's organs. Nearly half of them demonstrated their willingness to do so.

On the other hand, Rene *et al.* (1995) working in the USA found that more than eighty-five per cent would donate their organs only to family members. Interestingly, they found that some of the respondents believed offering some type of compensation would encourage relatives to donate organs. However, in a Gallup survey (1993), more than eighty per cent said incentives would have no effect on their decision to donate. Burroughs *et al.* (1998) emphasised that people should be encouraged not only to sign an organ donor card, but also to have discussions with their relatives and friends about their wishes.

I shall now turn to the studies in the literature involving the UK Indo-Asians community since they form the specific population that is the focus of the work reported in this thesis.

2.4 The attitude to organ donation in the UK Indo-Asians community

In the United Kingdom, although there is a low rate of organ donation among ethnic minorities, it has failed to provoke much active research. This is as true for the Indo-Asian community as it is for others. There are very few published studies that address the issue of attitudes to organ donation in the Indo-Asian community. They are listed in Table 2.4.1.

AUTHORS	LOCATION	SAMPLE	METHOD
Exley *et al.* (1996)	Coventry	22	Interview & focus group
Randhawa (1998)	Luton	64	Focus group & interview
Ahmed *et al.* (1999)	London	100	Structured questionnaire
Darr & Randhawa (1999)	Luton	64	Focus group & interview
Sheikh & Dhami (2000)	London	25	Structured questionnaire

Table 2.4.1 UK studies of attitudes among Indo-Asians

The first study to investigate Indo-Asians attitudes toward organ donation was conducted in Coventry and considers the attitudes of the Sikh community (Exley *et al.*, 1996). They found that most of the respondents showed concerns about "cutting up" the body after death and the idea of mutilating the body of a loved one. In terms of religious beliefs, a number of respondents were concerned that, if the deceased's body did not have certain organs, it would not be reincarnated. Some respondents felt that it is "sacrilegious" to take anything from the deceased body. They found that a few respondents were uncertain exactly what stance the Sikh religion took on this issue.

Exley *et al.* (1996) found that the older members of the community derived great status from their seniority and that their views had a significant impact on the decisions of younger members. An important role for the extended family is a feature common to all Indo-Asians cultures and has a strong influence on behaviours and attitudes.

This study showed that there was a strong association in their minds between their knowledge about organ donation and current practice in India, where organs are exchanged for money. They expressed a desire that organs should be allocated equally and that they should not be taken from poorer members of society for the benefit of rich people. A few of the respondents wondered whether organs were actually sold abroad by the NHS, indicating a mistrust of health care professionals and lack of awareness of the health care system in the UK.

Although most of the respondents in the study of Exley *et al.* (1996) showed a supportive attitude to organ donation for transplantation, only three out of twenty-two respondents carried an organ donor card. On the other hand, concerning the campaign run by the Department of Health, respondents agreed that the message in general and the specific published material addressed the main questions and queries they had regarding organ donation. However, they continued to need more assurance on the fact that organs were allocated justly.

Respondents suggested that patients from the same community, those who had already received a transplant and those who were still on the waiting list, should participate in community education campaigns with community leaders to encourage members of the Indo-Asian community.

This study can be criticised because the sample and sampling procedure were not made clear. The respondents were identified and selected purposely through consultation with members of the Sikh community already known to the research team. This might have introduced a bias. Furthermore, prior to the interview, a copy of available existing leaflet produced by the Department of Health was sent to each respondent in advance of the study, which might have influenced their responses.

A qualitative exploratory study conducted by Randhawa (1998) on an Indo-Asian population in Luton showed that the main factors for respondents deciding not to donate their organs was that they had not given the issue "serious thought" and they did not know what their religion's stance was on the issue. He stressed that was particularly important for followers of Islam (Muslims). Despite this, Randhawa came to the conclusion that culture and religion played a much less prohibitive part in the decision to donate organs in the Indo-Asian community as a whole. In respond to the finding of this study, Shaheen (1999) stressed that Muslims were "governed" by Islam. He stated that obtaining the opinions of religious leaders was important if there was to be a successful transplant programme.

The first study conducted in the London Indo-Asian community was by Ahmad *et al.* (1999). They interviewed 100 Indo-Asian people: fifty men and fifty women. They found that ninety per cent of the respondents were aware of organ transplantation. However, only sixteen carried organ donor cards. When asked about the reasons for not carrying a card, thirty-three per cent said that they had "never heard of it", while twenty-six per cent mentioned "personal feelings" and seven per cent were unsure of the standpoint of their religion. Of the seven respondents who were not sure whether their religion allowed organ donation, six were Muslim. In addition, they found that forty-

eight per cent of non-card-carriers would be willing to donate their kidney to a close relative.

Ahmad *et al.* (1999) extracted some suggestions from the participants as to how it might be possible to encourage the Indo-Asian community to adopt a more positive attitude to organ donation. These included use of the Asian media, attempts to gain and publicise religious approval, and recruiting community leaders as advocates. They also concluded that the main reason for the low rate of organ donation by Indo-Asians was the lack of knowledge.

However, that study had some limitations. Their sampling methodology was not mentioned. Furthermore, because a structured questionnaire was used in their study, more than one third of the participants chose the option "other" as their reasons for not donating, which indicated that there were important factors that were omitted from this study.

A survey conducted by Darr and Randhawa (1999) among Indo-Asians in Luton to assess their awareness and attitudes to organ donation found that most of the respondents obtained their knowledge about organ donation through their experience of people within their own community. They found that almost half of the respondents "had never seen" an organ donor card and did not know what it was for. Only three women carried an organ donor card. The main aim of this study was to generate more detailed information regarding Indo-Asian attitudes toward organ donation for transplantation. They found that the majority were aware of live kidney donation. Television was the main source of their information, followed by local community radio and leaflets in their GP's clinics.

Darr and Randhawa also found that the main obstacles to their respondents being willing to donate organs were that they did not take the issue seriously and, particularly for Muslims, they were uncertain of the rules of their religion on this issue. They concluded that detailed information relating to organ donation and transplantation had been obtained

through the experience of people within the community. They stressed that respondents had superficial views and knowledge about organ donation.

The only study that focused on UK Indo-Asian Muslims was conducted by Sheikh and Dhami (2000). They found that almost half (12/25) of the respondents were unwilling to donate their organs, whilst only three participants were willing to donate and the rest were not sure. Furthermore, they found that young Muslims educated in the UK were uncertain regarding this issue. They suggested that the Muslim Law Council's Fatwa (religious opinion) might encourage donation. However, since these authors used a structured questionnaire to collect data, they could not report further about the reasons underlying these responses.

There is a debate about the role of religion on the desire to donate organs. Despite the fact that Randhawa (1998) found that religious rulings were important to Muslims Indo-Asians, he concluded that religion was not a main factor for the Indo-Asian community at large. I have highlighted the data from Randhawa and Ahmad *et al.* that suggest that attitudes to donation may be different in Muslims and non-Muslims Indo-Asian communities. Also, I have highlighted the study of Sheikh and Dhami (2000), which substantiates this in a more detailed formal study. These data suggested the need for a more detailed and focused study on this group. That is the subject of the current thesis.

Before proceeding to describe my own work, I shall briefly review data from studies of non-UK Muslims group on the attitude to organ donation and transplantation.

2.5 The attitude to organ donation of Muslim communities outside the UK

Organ donation for transplantation is being successfully developed in some Islamic countries, such as the Kingdom of Saudi Arabia (KSA), which is considered a pioneer in transplantation activities in the Islamic countries. The Saudi organ transplant program would not have succeeded without obtaining the opinion of religious scholar's that Islam does not object to organ donation (Shaheen, 1999). Al-Faqih (1991) argued that there is a strong correlation between an awareness of these positive Islamic rulings and the willingness to donate organs during life and after death.

The work of Aswad *et al.* (1992) showed that eighty two per cent of Saudis are aware of the presence of the National Kidney Foundation in the KSA. Eighty-eight per cent were aware that Islam accepts organ donation and ninety-two knew that humans could remain healthy with only one kidney. Literate and younger people were better informed and it was suggested that this category of people should be targeted in the effort to convince people to carry donor cards and make them readily available throughout the country.

As reflected in previous studies, religion and culture appear to play a crucial role in the public attitude to organ donation and transplantation. Bilgel *et al.* (1991) showed that 55.5 % of the Turkish public were willing to donate their organs after death, while 33.7% refused and 15.8% were uncertain. Bilgel *et al.* felt that the reasons for refusal were largely due to "a number of misconceptions". Some were concerned about the "wholeness" of their body and were afraid they would be cut into pieces in the process of resurrection (43.8%). Religious beliefs and the misconception that Islamic law prohibits organ donation was the main reason for 26.2%. The belief by some that organs will be needed in the second life was the reason for seven per cent. No reason was given by 23.1%.

In the study of Bilgel *et al.*, the participant's willingness to donate organs was clearly related to educational level and socio-economic status. It was also pointed out that extended families (with older members) donated less frequently because of the respected position of the elderly in a Turkish family. Families tended to turn to their older members for advice in making decisions. In addition, if the next-of-kin is a woman, she was usually not given the choice to decide whether to donate a dead relative's organs or not.

The effect of Islamic religious beliefs on Muslims views on organ donation has been reported in the work of Rachmani *et al.* (2000). They found that forty-five per cent of the Arab Bedouin in Israel believed that the Islamic religion prohibits organ donation.

In another study from Turkey, it has been reported that more than eighty per cent of religious people in Turkey stated that organ donation was an "honourable" human act that would be acceptable under Islamic faith. These groups were willing to donate their organs after death. Furthermore, about half of them stated that if a member of their immediate or extended family died, they would be in favour of donating that member's organs (Rowinski *et al.*, 1996).

The findings from these studies differ significantly from the implication of the UK studies on Muslims Indo-Asians with respect to their beliefs and willingness to donate. This uncovers the need to perform more detailed study than has been performed to date on the UK Muslim Indo Asian community.

2.6 Conclusion

Most studies suggest that people are generally aware of transplantation activities. However, that awareness varies from country to country. It depends mainly on educational campaigns and health care systems. Moreover, most of the studies have shown that demographic and socio-economic factors influence attitudes. In addition, there are indications that factors that frequently militate against donation are religious beliefs and cultural values that argue in favour of keeping a dead body intact.

Due to the strong correlation between Islam and a Muslim's willingness to agree to organ donation, in the next chapter, I shall report my investigation of Islamic literature to find out more about the issue of organ donation in Islam.

Chapter 3

Organ donation from Islamic perspective

3.1 Introduction

It was clear from the findings of the previous studies conducted in the UK on Indo-Asians (chapter 2) that although all the participants were aware of organ donation for transplantation, most Muslims Indo-Asian have some doubts about its acceptability. They indicated that they might need to seek the opinion of Muslim scholars. However, the views expressed as to the position taken by Islam on this subject were at variance with the opinions of more than twenty scholars from the Muslim Shariah Council in the UK who, on 26 August 1995 (see Appendix 2), stated that organ donation from both living related and cadaveric donors was permitted in Islam. This made it important to clarify *official* Islamic views on this subject.

The issue of organ donation for transplantation is a source of much concern in the Islamic world. It is important because the literature suggests that there is a strong correlation between the willingness to donate organs (both in life or after death) and positive Islamic rulings (Al-faqih, 1991). Daar (1991) stressed that favourable religious rulings should enable transplantation to develop rapidly in the Islamic World. The opinions of Muslim scholars play an important role in shaping Muslims' attitudes. In 1972, after the government of Singapore introduced the "opt-in" donation system in Singapore, Muslims scholars ruled that organ donation is not acceptable for Muslims, which prompted the government to deny Muslims access to organ transplant as recipients. However, during the 1980s, Muslims in Singapore started signing organ donor cards after the Muslim Fatwa Committee of the Islamic Religious Council of Singapore (the authority that decides on Islamic religious matters) ruled that Islam did actually allow kidney transplants in order to save lives (Rasheed, 1992).

In Ottawa, Canada, at the headquarters of the Kidney Foundation of Canada, leaders from different religious communities signed a "giant" organ donor card. Two of the signatories were local leaders of the Islamic community in Ottawa. The Foundation took this bold step after they found that more than 16% of Canadians considered their religion a barrier to organ donation (Reportage, 1997).

However, it seems that many Muslims still often do not favour organ donation. For instance, Salahi *et al.* (1998) argued that in Iran there is social resistance to organ donation based on religious beliefs. According to Qureshi (1990), organ donation has not been explicitly dealt with in Islamic Law and there are differences of opinions among Muslim scholars. However, he suggested that scholars from Muslim Arab countries consider it permissible, while scholars from the Indian subcontinent believe that it is not. These observations have raised many questions with regarding to the role of Islamic teaching and ruling in an individual Muslim's decision-making process. What is the role of the scholars? Why are there differences in the opinions expressed by Islamic scholars on the same issue? What do they mean by Islamic Law? And how is it different from other law? Are Muslims obliged to follow this Islamic Law?

It seems that this issue is very sensitive. This chapter attempts to clarify any disparity between the attitudes of Muslim Indo-Asians toward organ donation and the "official" Islamic perspective. The relationship between health and religion is discussed followed by a definition of how Islam reaches its legal rulings on a particular issue. In addition, contemporary thinking among Islamic scholars, on issues of health and medicine in general, and organ donation, in particular, will be examined.

3.2 Relationship between health and religion

Before I broach the specific issue of this chapter, I would like first to put it in the wider context of attitudes to health in religion. A review of articles of the OVID database published between 1995 and 2002 uncovered more than 7000 papers/articles containing religious terminology published in the medical literature (MedLine, Biomedical Collections and Mental Health Collection). Religious issues are attracting more and more attention from professional health-care researchers. Why are researchers interested in finding out the effect of religion on health? Are they concerned, for example, whether religious practice promotes health? What is the significance of religion in health care?

Throughout history, medicine and religion have been interrelated to varying degrees. During the Middle Ages, medical and religious functions would often have been delivered by a single practitioner, a practice that continues in some cultures to this day. In Western medicine, after the 1600s, science claimed the "body" and relegated the "soul" to religious beliefs and practices (King and Bushwick, 1994). In Europe, for instance, most of the Christian churches used to provide health care services in monasteries built for this purpose and they also served as a health institutes to provide training for doctors and nurses. Although the Christian church felt a duty to help the sick and needy, they had no particular methods for treating disease beyond faith and prayer. At the time of the early Renaissance, however, tension emerged between science and religion, dramatized by the Church's confrontation with Galileo. As medicine became increasingly scientific, it came to see religion as a barrier to progress (Astrow *et al.*, 2001). From that time, they were separated. Today, we continue to see evidence of this classification as the studies of medicine and religious beliefs are often considered to be disparate or mutually exclusive (Levin *et al.*, 1997).

Although in the middle of the 19th century medicine and religion were nearly completely separated, some physicians have tried to reconnect them. In 1910, Dr William Osler, a pioneer of modern scientific medicine who wrote an article about "the faith that heals", explored the premise that one's religion influences health and healing. He stressed that

physicians should a consider patient's religion or spiritual factors as importantly influencing risk, etiology, therapy, prognosis, and recovery (Osler, 1910).

Recently, the World Health Organisation (WHO, 1998) asserted that the definition of health includes four domains of well-being: physical, mental, social and spiritual. The question that arises here is: what is the difference between religion and the spiritual domain?

The terms "religion" and "religious" are often used in the same breath as terms such as "spiritual" and "spirituality". According to the Encyclopaedia of Religion and Ethics (Hastings, 1971), the first two words are from the Latin *religare*, which mean "to bind together", while "spiritual" is from the Latin *spiritualis*, which means, "breathing in and out". Many authors have stated that it is not easy to achieve a precise, universally acceptable definition of religion and spirituality, because of the vast differences between the traditions that are commonly categorised as "religions". However, they report that many philosophers of religion today regard this difficulty of definition and diversity of religions in a positive light (Clarke *et al.*, 1993; Taliaferro, 1998; Thrower, 1999). Rather than advance a narrow definition from the beginning of what constitutes a religion, there are advantages to demarcating a "religion" simply by appealing to the examples that most people recognise as religions.

In brief, a number of specialists in religious studies have commented on the difficulty of defining religion or spiritual phenomena. Over the centuries, specialists have offered definitions, each according to their own perspectives. Religion and spirituality are among the most certain cultural characteristics giving structure and meaning to human values such as beliefs, practice, feeling, mood, attitudes, etc. (Hastings, 1971). According to Gove (1961), a religion may regulate the spiritual experience of a group of people into a system of beliefs and practices. On the other hand, he argued that the features of spirituality include broader concepts than religion and that there is a dynamic between them, which includes a quest for meaning and purpose, transcendence, connectedness, and values.

However, Holland *et al.* (1998) argued that religion and spirituality are overlapping concepts that may involve a search for meaning and purpose. Recently, Koenig *et al.* (2001) defined spirituality as individual thought about life and its meaning, while, by contrast, he defined religion as a belief system, practice, rituals and symbols that shape an individual and his/her responsibility to others living together in a community.

From this perspective, it may be argued that the perceived values embraced by an individual have the ability to motivate that individual's lifestyle towards fulfilment of their individual needs, goals and aspirations, leading to the ultimate achievement of self-actualization. Further, this process of self-actualization encourages the individual towards a spiritual quest that is unable to exist outside the human plan, and is solely dependent on the individual's ability to be self-sufficient. Thus, from these two perspectives, it is apparent that each individual has spiritual needs regardless of whether the individual is religious or not. Some people who regard themselves as spiritual do not affiliate in any way with a formal religion. Religious involvement and spirituality are overlapping concepts. Because of this overlap, religious involvement and spirituality are considered together in this chapter.

Religion has occupied an important dimension in most societies and continues to play an effective role in virtually all aspects of the past and recent contemporary life. Most of the humanitarian sciences attempt to explain human behavior in connection with religion. For instance, in the discipline of sociology, studies of religion have enjoyed a distinguished tradition, including prominence in the works of Emile Durkheim, Max Weber and Karl Marx.

The sociology of religion is a social science that objectively seeks to understand religions and religious phenomena in their varied manifestations as social activities shaped by societal conditions. One of the pioneers in this field was Max Weber (1864–1920) who wrote a book called *"The Sociology of Religion"*. In this book, Weber was quite dynamic and positive about religion. He described religion as an instrument for shaping and changing society and tried to work out what aspects of Western religious attitudes or

culture shaped the formation of Western society. These studies enriched social science by addressing topics such as religious movements, religious organisations and social change.

Religion has gained prominence in health research in recent years as indicated in the introduction to this chapter. Studies have shown that religious practice promotes health-related behaviour and lifestyles, which lower disease risk and enhance well-being, as well as providing social support, which in turn buffers stress and enhances coping (Chapman, 1986; Levin, 1987). In the United States, it has been demonstrated that religious practices represent the most prevalent complementary and alternative therapies (Eisenberg, 1998).

One study reported that 82% of Americans believe in the healing power of personal prayer, 73% believe that praying for someone else can help cure their illness, and 77% believe that God sometimes intervenes to cure people who have a serious illness (Yankelovich, 1996).

Indeed, some researchers have recommended that health professionals consider the religious orientations of their patients when planning or implementing a clinical treatment plan. There is evidence that patients also want health professionals to consider their religious commitment.

Many people desire frequent and more in-depth discussions about their religious needs with their physicians. In a survey conducted by King and Bushwick (1994) in North Carolina, USA, 77% of patients thought their physicians should consider their religious needs, while 48% of patients wanted their physician to pray with them. 68% of patients showed resentment that their physician had never discussed their religious beliefs with them.

These findings were supported by Ehman *et al.* (1999) in Pennsylvania when they examined patients` opinions about whether they would want their physician to inquire about their religious beliefs. They found that almost 94% of the patients strongly agreed that they would like their physician to ask them about their spiritual or religious beliefs.

From another perspective, Mardiros (1989) stressed that religion and spirituality were reflected in parents' beliefs in many ways. He found that some parents believed God was punishing or testing them by giving them a disabled child, while others believed God had selected them for unknown reasons, and still others thought God did not intervene to give them a disabled child, but that He was assisting them in their child's care. He concluded that parents often prayed for help from God, and some wished that the clergy were more helpful.

Studies on the influence of religion and spirituality on health, illness, and well being have shown statistically significant relationships and confirm the importance of spiritual and religious beliefs in medical practice. Several studies have reported that religious and spiritual factors have a significant effect on mortality (Goldman *et al.*, 1995; Strawbridge, 1997; Oman *et al.*, 1998; Koenig *et al.*, 1998; Glass *et al.*, 1999; Hummer *et al.*, 1999; Clark *et al.*, 1999), less cardiovascular disease (Oxman *et al.*, 1995), lower blood pressure and less hypertension (Koeig *et al.*, 1998; Walsh, 1998; Hixson *et al.*, 1998), and on mental health (Dein and Stygall, 1997; Wallace and Forman, 1998; Strawbridge *et al.*, 2001).

Furthermore, studies have shown that religious involvement is associated with health promotion behaviours such as more exercise, proper nutrition, more seat belt use and smoking cessation (Oleckno and Blacconiere, 1991; Wallace and Forman, 1998; Strawbridge *et al.*, 1997). Religious involvement also predicts greater functioning among disabled persons (Idler *et al.*, 1997). Finally, religious involvement is associated with fewer hospitalisations and shorter hospital stays (Koenig *et al.*, 1998).

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On the other hand, strong resistance remains among some health care professionals, especially within the academic field, to consider religion in the field of health sciences. They may believe that religion is unimportant because it is "unscientific" or because it means little to them personally (Berry, 2000; Bolton, 2002; Koenig, 2002; Lanciani, 2002; Leibovici, 2002; Neumann, 2002; Smith, 2002; Thornett, 2002; Twisselmann, 2002). Levin (1987) argued that there is insufficient evidence that religious activity is significantly related to health. He argued (1994) that religion is not "real" and that, although it may matter to some patients, in the clinical setting it is mostly a nuisance to be overcome. He believed that research which supports religion is, *a priori*, "bad science".

Some studies have suggested that there is no relation between religious activity and health. Aviles *et al.* (2001), in their study of 799 patients in critical care units, reported that intercessory prayer had no significant effect on medical outcomes after hospitalisation. Indeed, Sloan *et al.* (1999) strongly believed that the evidence of an association between religion and health is "weak and inconsistent". They stressed that it is premature to promote faith and religion as adjunctive medical treatments. In addition, Sloan *et al.* (2000) argued that religion could not be words used, as one uses antibiotics or surgical intervention, to treat patients. They stressed that evidence for any effect of religious activity is "generally weak and unconvincing". They believed that physicians should not take it on themselves to prescribe spiritual or religious practice, because of the authority that families and patients assign to what a doctor says, and the related risk of abusing power.

However, Miller *et al.* (2001) confirmed that a large and growing number of studies have shown a direct relationship between religious involvement and positive health outcomes. Levin *et al.* (1996) argued that social scientists have documented the importance of religious beliefs, behaviours and affiliations for interpersonal behaviour, family life and human development. Psychiatrists recommend spiritual assessment, however, as an integral part of medical history taking, and the diagnostic and statistical manual of mental disorders now recognises religion and spirituality as relevant sources of either emotional

distress or support (Larson *et al.*, 1993; and Turner *et al.*, 1995). Koenig *et al.* (1999) imply that even in the absence of supporting evidence regarding the relationship between health and religion, it would still be permissible for health professionals to recommend that patients engage in religious activities because such activities provide comfort.

Research has increased the validity of religion and spirituality as topics for still further health professional research. For instance, a conference held in 1995 titled "Methodological approaches to the study of religion, health and aging" and another titled "Spiritual assessment in health care setting" were sponsored by the National Institutes of Health (NIH) which had funded researchers to investigate the effect of religion activities on physical and mental health. In this series, the John Templeton Foundation has also funded conferences, studies and dissemination of findings on this topic. In 1996, with the cooperation of the NIH, the American Association for the Advancement of Science sponsored a symposium titled "Religious factors that influence disease states" and convened a workgroup entitled "Measures of religiousness and spirituality" which was also supported by the Fetzer Institute (Wallis, 1996).

Moreover, there are now nearly more than thirty medical schools in the United States with taught courses on religious and spiritual issues. Around eighteen medical schools have received grants to sponsor courses that inform future physicians of the role of religion and spirituality in the lives of patients and provide students with tools to address these issues (Levin *et al.*, 1997). These efforts acknowledge patients' spirituality and bring it into the mainstream of health education, research and clinical care. They also provide opportunities for health professionals, students and physicians to learn how to assess, respect and incorporate patients' spiritual perspectives.

To some health professionals, that religious involvement or spiritual factors could beneficially affect the health and clinical course of individual patients may seem implausible. Even those more sympathetic might think that little if any published research has either supported or refuted this point. In fact, researchers have begun addressing the relationship between health and religion, identifying known or

hypothesised biobehavioral or psychosocial pathways through which religious or spiritual practice may promote health or prevent disease (Dossey, 1995). The consistency and robustness of earlier studies have led to the emergence of a growing body of research on "the epidemiology of religion", "sociology and religion", and "psychology and religion".

In the UK, the Department of Health released the Patient's Charter in 1991. This requires that health care providers should ensure "respect of privacy, dignity, and religious and cultural beliefs". One way of helping to ensure that such respect is shown is through the appointment of hospital chaplains. The role of the hospital chaplain in the National Health Service (NHS) is to respond to both the religious and spiritual needs of patients and others. Religious and spiritual needs are not distinct and separate from each other, but do help in defining the role of the chaplain, what the special needs of the specific hospital are and, to a lesser extent, the expectations of his or her own denomination.

Hospital chaplains in the UK need not always, however, be Christian. In most large hospitals, there will be key religious representatives of other religions, such as a local Jewish Rabbi or Muslim Imam, who will act in a chaplaincy role. In the light of the resolution in the Patient's Charter, the NHS released the subsequent NHS Management Executive document, HSG (92) 2, which required provision for religious needs of all patients.

It is clear that religion has become an important issue in health. In the following sections, I shall discuss the relationship between Islam and health issues and relate them to organ donation.

3.3 Background to Islam

To understand Islam one must understand its assumptions and the basic tenets of the religion. The word *Islam* is derived from the Arabic root *Salaam*, which means, among other things, peace, purity, submission and obedience. In the religious sense, the word Islam means submission to the will of God and obedience to His Law. The believers in Islam are called Muslims. The word "Muslim" is based on the same Arabic root as Islam and means "one who is obedient". Muslims believe there is only one God, known as "Allah", and that Muhammad is His prophet. The revelation that he received is called the *Qur'an*, while the message is called Islam. The language of the *Qur'an* is Arabic. Muslims all over the world try to learn Arabic so that they may be able to read the *Qur'an* and understand its meaning. They pray and practice Islam in the language of the *Qur'an* (Abdalati, 1975).

Allah Himself, is regarded as the original founder of Islam as and the date of the founding of Islam goes back to the age of Adam. Thus, Muslims believe that Muhammad was a successor to the prophets of the Judeo-Christian Bible, and that he reinforced and immortalised the eternal message of God to mankind. The religion of Islam is the complete acceptance of and obedience to the teachings of Allah, as revealed to His prophet, Muhammad (Endress, 1988).

Because Islam means submission to will of Allah, Muslims must accept and show obedience to what is stated in Islamic literature. The primary legal source upon the authority of which all Muslims agree, and which formed the basis of legislation at the time of Muhammad is the *Qur'an* (Brown, 1996). It is divided into 114 *Surah* (chapters) of unequal length, and each chapter is further sub-divided into *Ayah* (verses). Although there is only one edition in Arabic all over the world, there are many translations in very many languages.

According to the *Qur'an*:

> *These are the limits [set by] Allah, who will admit whosoever obeys Him and His Messenger (Muhammad) to gardens under which rivers flow (in Paradise), abiding eternally therein; and that is the great attainment (13). And whoever disobeys Allah and His Messenger and transgresses His limits, He will put him into the Fire, to abide eternally therein and he will have a humiliating punishment (14).*
>
> *Al-Nisa* (4:13–14)

3.3.1 Muslims in the UK

Muslims today comprise around one billion persons living in almost every country in the world. There are about two million in the UK. They are the largest religious 'ethnic minority' group in the UK, as well in the whole of Europe (Anwar, 2000). Muslims first arrived in Britain in significant numbers after World War II. However, the first records of Muslims in Britain go back to in the eighteenth century. That was when the British Empire included a number of Islamic countries, such as Nigeria, Egypt, India and Malaya. The first Muslims came to Britain in small numbers as seamen, soldiers or students. Later, during the 1950s, the flow of Muslims in much larger numbers started to supplement manpower (Matar, 1998).

As a result of large numbers of Muslims arriving in the UK during the 1950s, the need for places of worship developed. They started to build what are called *mosques* or *masjids,* derives from *sajda,* the Arabic for "prostration". For purposes of clarity, the more widely recognised term "mosque" has been substituted for the equivalent *masjid* in this thesis.

The word *masjid* was first used during the life of Muhammad, who built the first *masjid* during his prophet-hood in Medina (AD 622), in the present day Kingdom of Saudi Arabia. The mosque has always played an important social role in Muslim life. In the

early Islamic period, the mosque was not only a place of worship, but also functioned as a centre to serve the community. It was used as a school to educate Muhammad's followers and it was where he delivered his addresses to deal with issues surrounding the social life of the community. He also used it as a place where the leaders of the community could deal with internal and external political activities.

After Muhammad, Muslims became particularly interested in the educational role of the mosque. They built mosques wherever they lived and designed them to serve the special needs of the local Muslim community. Therefore, it can be understood how the mosque come to act as a focal point in a Muslim's life.

The first mosque in the UK was founded in 1860 in Cardiff. Then, during the 1900s, there was a slow establishment of new mosques. The Union of Muslim Organisations was founded in the 1970s. After that, during the 1990s, there was a jump in the numbers of mosques on account of the immigration of many Muslims into the UK (Matar, 1998). The first Islamic Centre opened in London at Hanover Gate in Regent's Park in 1944. It was donated by King George VI in memory of the thousands of Indian Muslim soldiers who had died defending the then British Empire.

During the 1980s, the UK Muslim community continued to grow and more such Centres were needed. Islamic Centres are currently experiencing tremendous growth. There are now more than 150 in London alone.

I now turn to the question about how Muslims extract rules from the *Qur'an* and *Sunnah*, the use of other sources, and the meaning of Islamic Law.

3.3.2 Islamic Law (*Shariah*)

Islamic Law has been called the *Shariah*, which is an Arabic word meaning a clear straight way, or path. It is the most impressive monument to the religious culture of Islam. It refers to the collection and compilation of Islamic laws based on the *Qur'an* and the *Sunnah*. *Shariah*, the legal code of Islam, is not bound by time and place and is designed to cater to the different needs of Muslims all over the world (AboZahrah, 1958).

Muslim scholars derived from the *Sunnah* a methodology for formulating laws in Islam called *Usul al fiqh*. It is a complete practice and has its own sources, proofs, principles and methods. It refers to the legal rulings of the Muslim scholars, based on their knowledge of the *Shariah* (Al-Alwani, 1990).

Different schools have emerged (*Hanafi*, *Maliki*, *Shafi* and *Hanbali*), each with its own interpretation and application of Islam. These schools of thought have minor differences justified by their different interpretations of the *Qur'an* and *Sunnah*. Differing viewpoints sometimes exist even within a single school of thought. There is, however, no dispute among Muslims that the *Qur'an* is the basis of the *Shariah* and that its specific provisions are to be scrupulously observed, and that the *Sunnah* is a complementary source to the *Qur'an*, and all Islamic laws are deduced from them (Brown, 1996).

Muslim scholars have developed other methods to extract law from the *Qur'an* and *Sunnah*: *Ijtihad*, *Ijmah* and *Qiyas*. These methods were developed after Muslims faced several issues not explicitly covered in the *Qur'an* and *Sunnah*. Indeed, in the *Ijtihad* (an Arabic word meaning "progressive reasoning by analogy") Muhammad set a precedent for his companions and later Muslims that clearly proved the legitimacy of *Ijtihad* (Al-Alwani, 1990). According to Kamali (1991), the companions of Muhammad had split into two groups over the interpretation of the prophet's instructions, with one group adopting the literal or explicit meaning of his injunctions, while the other adapted a meaning, which they considered suitable for a given situation. The fact that Muhammad approved of both groups showed that each position was legally as valid. Hence, when

Muslim scholars could not find an explicit legal ruling in the *Qur'an* or *Sunnah*, they were to make use of *Ijtihad* in order to arrive at a judgement on their own. Moreover, probably to establish and reinforce this concept, Muhammad ordered some of his companions to make *Ijtihad* on certain issues during his life.

The second source of the *Shariah* is *Ijmah*. It is the result of a consensus of the scholars on an issue. A series of conferences and seminars have been held recently in which the most knowledgeable scholars participated to discussed certain issues. However, the concepts and ideas found in the *Ijmah* are not found explicitly in the *Qur'an* or the teachings of Muhammad. Islamic judges are able to examine the *Ijmah* for many possible solutions that can be applied in a modern technical society. They are free to create new and innovative methods to solve social problems based upon the concepts found in the *Ijmah*. These judges are allowed great discretion in applying the concepts to a specific problem (Ibrahim, 1997).

Qiyas means "analogy" or reasoning on the basis of similar circumstances. It also means a reference or a comparison of one thing with a similar one. It can also be applied in circumstances where guidance from the *Qur'an* and *Sunnah* is not directly available. A process of deduction reaches a solution to a problem by drawing parallels with similar situations in the past.

It is important to mention here that not anyone can deal with *Shariah*. A scholar should be expert in Arabic to the extent that he understands the *Qur'an* and the *Sunnah* both linguistically and legally, and how they fit in the spirit of revelation and Islam (Sharfaldeen, 1983). He should also be well acquainted with the *Qur'an* and the methodology for interrogating the sources in the *Shariah*. In addition, he should be well versed in the Prophetic tradition (AboZahrah, 1958).

Muslims used the terms *Ulama*, *Shikh* and *Mullah* as labels for their religious scholars. Muslim scholars are frequently consulted on many important issues in daily life. Nowadays, Muslim scholars are often graduates of Islamic universities and they are charged with interpreting and contextualising religious teachings for the wider Muslim community.

Islam has no other clergy. Any Muslim scholar is able to address a *fatwa* in any given situation according to the principles of *Shariah*. However, variances in the responses to contemporary questions are traceable to methodological differences in understanding or authentication of the primary interpretation of the text of the *Qur'an* and the *Sunnah* (Brown, 1996).

It is said that all of the laws in the *Shariah* are promulgated to protect what are described as the five most important "indispensables factors" in Islam: religion, life, intellect, offspring and property. *Shariah*, in fact, has adopted two courses for the preservation of these five factors; the first is through cultivating religious consciousness in the human soul and awakening of human awareness through moral education; the second is by inflicting deterrent punishments, which is the basis of the *Shariah* system (AboZahrah, 1958).

There are many statements in the *Qur'an* and *Sunnah* addressing health issues. I will describe these in the next section.

3.3.3 Health guidelines in Islam

Islam considers health to be one of the greatest blessings to have been given to human beings by Allah. Indeed, it is considered the greatest blessing after faith itself. It is part of the duty of every Muslim, therefore, to safeguard this blessing and not to allow it to deteriorate through ill usage. Otherwise, he/she will be severely punished.

It is acknowledged that the preservation of this blessing can only be achieved through taking good care of one's health and taking every measure to maintain and enhance it. Moreover, the *Qur'an* and the *Sunnah* contain teachings that shows every Muslim how to protect his health generally and how to take care of each of his organs. In addition, a number of statements in the *Qur'an* and the *Sunnah* prescribe certain medicines for certain diseases (El-Kadi, 1993).

However, when I speak of health, I do not restrict myself to medicine as it is commonly understood nowadays, meaning curative medicine. Health care professionals of former and present times agree that there are two types of medicine: preservation of the health of those who are healthy, and restoration of health to the sick through medication and rehabilitation.

The *Qur'an* is not a book of medicine or of health sciences, although there are in it hints which lead to good health. The *Qur'an* achieves its healing and health-promoting effect by utilising three different approaches: the legal, the guiding and the direct healing approaches.

Sometimes the *Qur'an* takes a legal approach, through legislation, to prohibit lifestyle and behaviour which are hazardous to health, and prescribes behaviours that promotes health. Examples of the second guiding approach, which suggests activities believed to promote health include: moderate eating, abstinence from alcohol and tobacco consumption and other psychoactive substances, regular exercise, prayer, fasting, ablution and bathing, and breast feeding; there are many other similar such injunctions.

The third approach is to specify activities which the *Qur'an* says have a direct healing effect of the *Qur'an* on the various systems of the human body (El-Kadi, 1993). According to Al-Jauziyah (1999), there are two types of diseases mentioned in the *Qur'an*, the diseases of the heart and illness of other parts the body. Sickness of the heart is described as doubt, misgiving and the sickness of desire and aberration (*Qur'an*: *Al-Maidah* 5:52; *Al-Anfal*, 8:49; *Al-Tauba*, 9:125; *Al-Nur*, 24:50; *Al-Ahzab*, 33:12, 32, 60; *Mohammad*, 47:29; *Al-Muddathir*, 74:31).

Concerning the disease of doubt, the *Qur'an* says:

> *In their hearts is a disease (of doubt and hypocrisy), so Allah has increased their disease; and for them it is a painful punishment because they [habitually] used to lie.*
>
> (*Al-Baqarah*, 2:10)

> *O mankind, there has come to you instruction from your Lord and healing for what is in the breasts, and guidance and a mercy for the believers.*
>
> (*Yunus*, 10:57)

> *[That is] so He [Allah] may make what Satan has thrown in by a trial for those within whose hearts is a disease [of hypocrisy and disbelief] and those who are hard of heart. And indeed, the wrongdoers are in extreme conflict.*
>
> (*Al-Hajj*, 22:53)

Also, the *Qur'an* states that Allah has the power of healing from diseases:

> *And when I am ill, it is He who cures me.*
>
> (*Shuara*, 26:80)

Some physical illnesses are also mentioned in the *Qur'an* (*Al-Baqarah*, 2:196; *Al-Nisa*, 4: 43, 102; *Al-Maidah*, 5:6; *Al-Muzzammil*, 73:20; *Al-Taubah*, 9:91). The *Qur'an* explicitly diminishes some demands of *Shariah* law in the context of physical sickness:

> *There is not upon the blind any guilt or upon the lame any guilt or upon the ill any guilt.*
>
> (*Al-Fath*, 48:17)

> *The month of Ramadan in which was revealed the Qur'an, a guidance for the people and clear proofs of the criterion. So whoever sees the month [of Ramadan], he must fast, and whoever is ill or on a journey then an equal number of other days. Allah intends for you ease, and does not intend for you hardship.*
>
> (*Al-Baqarah*, 2:185)

There are some specific treatments mentioned in the *Qur'an.* For example:

> *And your Lord inspired the bee, saying: take for yourself houses among the mountains and among the trees and that which they [people] construct (68). Then, eat from all fruits, and follow the ways of your Lord has lain down [for you]. There emerges from their bellies a drink, varying in color, in which there is healing for people.*
>
> (*Al-Nahel*, 16:68–9)

For diseases affecting the heart and mental capacity, the *Qur'an* prescribed recitation:

> *And We send down of the Qur'an that which is a healing and mercy for the believers.*
>
> (*Al-Isra*, 17:82)

As I mentioned early in this chapter, *Shariah* identifies the five most important "indispensables" in Islam, one of which is life itself. The *Qur'an* strongly stresses the protection the human life:

> *Whoever killed a person not in relation to murder, or [and] to spread mischief in the land – it would be as if he killed all mankind, and if anyone saved a life, it would be as if he saved the life of all people.*
>
> (*Al-Maidah*, 5:32)

As we can see from the verses quoted above, the *Qur'an* considers two types of diseases, the psychological and the physical. It also encourages people to seek treatment and to keep as healthy as possible. It prescribes ritual activity for psychological disease while seeking medical help for physical diseases. In addition, sick people are excused many of their religion obligations.

On the other hand, as mentioned above, Muhammad is also said to set an example to Muslims so his traditions in matters of health and personal hygiene are also taken as a guide for his followers. This has been called "prophetic medicine". It is refers to the words and actions of Muhammad that have a bearing on disease, and the treatment and care of patients. These also include the words of Muhammad on medical matters, treatments practiced by himself and others, treatments observed by Muhammad without his objections, medical procedures that he had heard or knew about and did not prohibit, and medical practices that were so common that the Muhammad could not have failed to know about them.

However, it is important to mention that Muhammad's medical teachings are viewed as being specific for place, population and time (Al-Jauziyah, 1999). Some are suitable in a particular environment, considering its climate, temperature and other factors, such as the desert environment of Arabia. These cannot be applied universally, as explained by Salim (1995). However, Rahman (1998) argued that prophetic medicine also included

general guidance on physical and mental health that is applicable to all places, all times and all circumstances. Muhammad said:

> *There are two blessings, which many people do not appreciate: health and leisure.*
>
> (Al-Jauziyah, 1999)

And he said:

> *No blessing other than faith is better than well-being.*
>
> (Al-Jauziyah, 1999)

Good health is something for which Muslims are accountable to Allah. Muhammad said:

> *The first thing every servant of Allah will have to account for on the Day of Judgment, that he will be asked by Allah: Have I not given you a healthy constitution and have I not quenched your thirst with cold water?*
>
> (Al-Jauziyah, 1999)

And:

> *No one will be allowed to move from his position on the Day of Judgment until he has been asked how he spent his life; how he used his knowledge; how he earned and spent his money; and in what pursuits he used his health.*
>
> (Al-Jauziyah, 1999)

Some prophetic medicine reflects only what the Arabs at the time had found useful by experience. Muhammad's speech provides an example:

> *If there is any good [or he might have said 'cure'] in any of your medications then it will be that in an incision to bleed, or in a drink of honey, or in cauterization, matching the illness [of which one complains]. As for me, I do not like cauterization.*
>
> (Al-Jauziyah, 1999)

What is important in this aspect of medicine, the curative aspect, is that Muhammad approved the principle of medical treatment and encouraged his followers to seek it. He is quoted as saying:

> *Yes, servants of God! Seek medical treatment.*
>
> (Al-Jauziyah, 1999)

Muhammad raised the hopes of patients, making clear that all diseases can potentially be cured:

> *God has not created a disease without creating a cure for it*
>
> (Al-Jauziyah, 1999)

He also urged doctors to try to identify those cures, pursuing the necessary research for this purpose. Muhammad said:

> *Every disease has a cure. If treatment is administered with the right cure, the patient will recover by God's grace. God has not created a disease without creating a cure for it, which may be known to some and unknown to others.*
>
> (Al-Jauziyah, 1999)

Nevertheless, Muhammad placed the whole issue of the effectiveness of treatment in the context of divine will:

> *Do our supplication, medication and methods of prevention prevent anything that God has willed? These are also part of God's will.*
>
> (Al-Jauziyah, 1999)

Thus, he made it clear that one aspect of Allah's will may be prevented by another. It seems, therefore, that Islam leaves no room for fatalism, even though it may be dressed up as reliance on Allah. Although disease occurs by Allah's will, every Muslim is commanded to try to protect himself against it by utilising methods of prevention – which also work by Allah's will. In that, as always, they should place their trust in Allah.

A similarly important point in relation to curative medicine is that Muhammad opposed so-called faith healing. He approved of medicine that relies on study and experimentation, seeking to relate causes to effects. However, he spoke against the practices of the pagan Arabs who discarded obvious causal relationships and laws of nature, preferring instead mysterious causes and powers, such as charms, talismans, incomprehensible jabbering and tricks practiced by sorcerers and quacks (Al-Akili, 1996).

> *Whoever wears a charm, may Allah never fulfill his purpose, and whoever wears a talisman, may Allah never let him enjoy peace of mind.*
>
> (Al-Jauziyah, 1999)

Support for medicine and the preservation of the health of those who are well, can clearly be seen to be part of Muhammad's guidance. The rules relating to health protection are general ones which fit in well with the natural laws that Allah has put in place to promote the well being of his creation.

3.4 The dilemma of organ transplantation in Islam

Organ donation and transplantation, continues to stir debate among scholars and organ transplant professionals in the Muslim world. This is largely because the subject has not been explicitly dealt with in the *Qur'an* or *Sunnah*. Furthermore, this issue is closely connected with life and death. Contemporary Muslim scholars have deliberated on the issue and proposed certain *fatwas* based on deductions from *Shariah* sources. They have attempted to determine the legality of organ donation through *Ijtihad*, *Ijmah* and *Qiyas* (Al-Alwani, 1990). In the following two sub-sections, I will demonstrate the two leading opinions.

3.4.1 Opposing opinions

Muslim scholars who oppose and addressed *fatwas* against organ donation and transplantation all originate from a limited number of countries, particularly Egypt, India and Pakistan. They believe that organ donation is not permissible on the basis of the sacredness of the body in Islam (Qureshi, 1995).

In Egypt, Al-Sukari (1989) stressed that a Muslim cannot dispose of his/her body on death. He argued that no one could donate his/her organs because of the following principles:

- The human body is the property of Allah. It cannot be donated either by the person him/herself or his/her heirs;
- Taking an organ from a living person does some harm to that person; and taking it from a cadaver is an act of mutilation;
- The results of organ transplantation are not encouraging, and sometimes they are dismal;
- The costs of such programmes are stupendous for both Third World governments and the populace at large;

- Profiteering is apt to occur. Many horrendous stories have been published in the media.

Furthermore, according to Syed (1998), the principal of Al-Azhar University in Cairo, Egypt, Sheikh Gad Al-Haq, stated in an interview that:

> *As long as the heart is still functioning, the person is not dead. Clinical death is not complete death. So removing an organ must not end his or her life, even if his or her condition is hopeless.*

Sheikh Al-Shaarawi, a well-known Islamic scholar from Egypt, supported this, saying:

> *Donation of a thing is an act of possession, in that you donate a property which you wholly own, but you do not donate a thing you do not own [indicating that the body is owned by Allah] and, hence, donation becomes lawfully invalid.*

This idea is echoed in certain Muslim circles. As a result, organ donation laws have not been formally approved as yet in Egypt (Hassaballah, 1996). This argument occurs among health professionals as well. One Egyptian doctor has argued that Muhammad indicated that any part amputated from man is like a complete dead body and it should be treated as such (Hassan, 1997). Hassaballah (1996) argued that the "Egyptian Parliament" has not yet approved organ donation because some Muslim scholars and health care professionals do not accept the diagnosis of "brain death". Al-Mousawi *et al.* (1997) supported this. Although some Muslim scholars do accept organ donation, the concept of brain death is not widely understood.

However, most Muslims still believe that cardiac death represents the true time of the departure of the soul from the body. Brain death possibly poses the greatest challenge to Muslim scholars. Congresses of scholars have accepted a new definition of death based on total brain death even though some physiological functions are still maintained by

artificial animation. The new definition was made possible through a process of analogy to a juridical rule that recognised the concept of a fatal injury. On 16 October 1986, the Third International Conference of the Organisation of the Islamic Conference – the Islamic Figh Academy –in Amman, Jordan released Resolution No. 5, which declared that:

> *A person (is) considered legally dead, and all the guidelines provided by the Shariah's principles of determining death are applicable, when one of the following signs is confirmed:*
>
> *- Complete cessation of the heart and respiration occurs, and expert physicians ascertain that the cessation is irreversible:*
>
> *- Complete cessation of all functions of the brain occurs, and expert physicians ascertain that the cessation is irreversible and the brain is in a state of degeneration. In this condition it is permissible to discontinue the life supportive system from the patient even when some of patient's organs such as the heart are kept functional by artificial means.*

The statement then proceeds to list the procedure that must be followed as a part of the previous assertion:

> *Brain death is the irreversible cessation of all spontaneous brain activity, including the brain stem. Before any supportive means is discontinued, family members must be counselled. This should be documented in the patient's chart.*

In order to define brain death from both medical and religious perspectives, the Islamic Organisation for Medical Sciences (IOMS) held a symposium in Kuwait in 1996 to discuss the medical definition of death from an Islamic perspective. They released what is known as the "Statement from the Islamic Organisation for Medical Sciences on the Medical Definition of Death" (Appendix 1). In it they stated that:

> *Upon these medical data, the religious jurists based the view that if a person has reached, with certainty, the state of brain stem death, then such a person has departed from his life, and all the Islamic rulings concerning death are applicable to him.*

This statement was more accurate in clarifying precisely what is meant by brain death than Resolution No. 5 of the Third International Conference of the Organisation of the Islamic Conference. IOMS tackles the ethical issues that emerged on the medical scene as an inevitable outcome of scientific progress. They have held various symposia to bringing together medical scientists and religious jurists to discuss the problems and their implications.

In this series of symposia it was concluded that Muslims were forbidden to violate, harm or mutilate a dead body, whether it is a Muslim or non-Muslim cadaver, as an act of revenge, to show disrespect or without any good reason. In regard to the prohibition of violating and mutilating the dead, Muhammad said:

> *Breaking the bones of a dead person is equal in sinfulness and aggression to breaking it while a person is alive.*
>
> (Al-Jauziyah, 1999)

Also, in the *Qur'an*, a person is forbidden from taking his own life:

> *Do not kill [or destroy] yourselves: For verily Allah has been Most Merciful to you.*
>
> (*Al-Nisa*, 4:29)

And:

> *Make not your hands contribute to your own destruction.*
>
> (*Al-Baqarah*, 2:195)

Certain scholars from the Indian subcontinent have expressed the same opinion. The Islamic Fiqh Academy of India, during its Second Fiqh Seminar, held 8–11 December 1989, in New Delhi, resolved that if a person directed that after his death his organs should be used for the purpose of transplantation, it would not be considered as a valid will according to *Shariah* (Zhorne, 1990).

They did discuss the issue from the perspective of the recipient and concluded that those organs from a person can be regarded as "danger-free" and "harmless" and that transplantation was therefore permissible from the legal religious point of view (Shafi, 1995).

However, it seems that most of the scholars who were against organ donation were concerned about organ trading that might benefit rich people at the expense of the poor, as Shafi (1995) stated:

> *If this system of treatment became prevalent, one of its immediate effects would be that the eyes, kidneys and other organs of poor people would be sold as a commodity on the open market.*

Islam condemns any organ trade. The selling of body organs is absolutely prohibited by Islam. This is because the human body is considered to have been given in trust by Allah (Mossa, 1993). Shahat (1999) described organ trading as an "affront" to human dignity. He argued that since organ donation saved many lives, it is an act of charity.

3.4.2 Favourable opinions

On the other hand, other experts have produced Islamic guidelines and religious opinions (*fatwa*s) that have been favourable towards the donation of organs for transplantation from both living and cadaveric donors. In 1979, the Committee of Fatwa of the Ministry of Islamic Affairs in Kuwait issued a pioneering *fatwa*, which stated that organ donation for transplantation is permissible in Islam.

Because of the rapid spread of transplantation in the 1980s, the Islamic world felt that it was important to generate a unified Islamic *fatwa*. However, the principle in Islam is that if there is more than one opinion, one ought to choose that of the most trusted scholar or to seek the assistance of others who can help in choosing the right answer. It is recommended, in such a case, that one choose the more conservative as opinions as the safest way.

The Organisation of the Islamic Conference – the Islamic Figh Academy – which represents Muslim scholars in Islamic countries, in their fourth conference (1988) in Jeddah, Saudi Arabia, after a comprehensive religious and medical discussion of organ donation and transplantation issued "Statement No (1)" in which they considered human organ donation from living and cadaveric donors and stated that they "are all permissible according to *Shariah*".

One of the most supportive of Islamic scholars with respect to organ donation and transplantation is Al-Qaradawi (1998) who declared that the attitudes of *Shariah* regarding organ donation and transplantation are "clear and unquestionable". He stated that:

> *There is no objection to the donation of cadaveric organs with the permission of the immediate family, for whoever needs these organs, considering also the desire for the redemption of the deceased.*

In the same *fatwa*, he addressed the dilemma that most Muslims have regarding donating to non-Muslims and also the case of using animal organs. He said:

> *Islamic Shariah does not see the need to prevent Muslims from donating to non-Muslims or vice versa. Organ transplantation from an animal (e.g., a pig) to a human should be considered only in case of extreme necessity.*

Finally, he stressed that medical organisations in the Islamic world should be informed of the legal Islamic opinion which is in favour of organ donation and organ transplantation as long as moral and religious conditions have been met. He considered any person who has been diagnosed as brain dead as completely dead.

The majority of Muslim scholars have allowed the donation of organs. However, they do not allow the sale of human organs. Their position is that the sale of human organs violates the dignity and honour of the human being, and so it would be an offence. Some scholars suggest that, because people have become too materialistic, it may not be possible to find a freely donated organ. However, some scholars allow the purchase an organ in situations of extreme necessity, but a Muslim should never sell his/ her organs (Al-Sharawee, 1997).

3.4.3 UK Shariah Council

In the UK, the Muslim community, which comes from different Islamic backgrounds, has a mixed view on the issue of organ transplantation (Sheikh, 1998). The Muslim Shariah Council in the UK has announced that it is acceptable for Muslims to donate organs and to receive transplants (Choo, 1995). The UK Shariah Council, which consists of scholars from all major Muslim communities in the UK together with three distinguished lawyers, has considered the issue of organ donation for transplantation and has made a statement that reflects the Council's resolutions.

They argued that the legal aspect of organ donation could be based on *Shariah* principles. They stated that a Muslim is forbidden from harming him/herself or others and, in the case of necessity, certain prohibitions are waived, such as when the life of a person is threatened by the prohibition on eating carrion or drinking wine. Moreover, they pointed out that a Muslim has the legal authority over his/her own body for the purpose of saving the life of another. Furthermore, they stressed that in Islam it is an obligation upon the sick to seek available up-to-date treatment.

Thus, based on the previously described Islamic principles, they agreed unanimously on a unified *fatwa*, which stated that:

- *It is permissible for a living person to donate part of his body such as the kidneys, to save the life of another, provided that the organ donation would not endanger the donor's life and might help the recipient.*
- *It is permissible to remove the organ of a dead person to be used to save the life of a sick person.*
- *It is permissible for a person to donate his body or parts of it to be used after death to treat those who need a transplant, so it is permissible for Muslims to carry a donor card.*
- *In the absence of a donor card being carried by the dead person, it is sufficient to obtain the consent of the next of kin.*

- *The proper authorities will act in lieu of relations if they are not known.*
- *Organ donation must be given freely without reward. Trading in organs is prohibited.*

However, is this *fatwa* acceptable to all Muslims in the UK? Although local representatives of UK Muslim communities have promulgated this *fatwa*, it has still not proved universally acceptable to all Muslim communities in the UK. Some believe it is based on racial motives and does not help the majority of Indo-Asians compared with other minorities.

However, this *fatwa* is more comprehensive than others are (Appendix 2). It gives Muslims more latitude to take advantage of organ donation. It prevents commercial misuse of organ donation by making a clear statement that it must be a free donation and that trading is prohibited. It also legitimises the organ donor card. This *fatwa* is very bold in comparison with others. It considers all the common questions regarding ownership and sacredness of the body. Moreover, it raises organ donation to the level of an honourable gift for humanity, regardless race or religion.

3.5 Conclusion

In conclusion, it is appears that religion and medicine were once linked, but that they have drifted apart as scientific advances have made medical care increasingly effective. Perhaps because of a sense that something is missing in medicine today, the religious aspect of health care has become a topic of intense health research. The findings in the published literature suggest that religion and spirituality might play a role in enhancing illness prevention, in coping with illness and in assisting recovery.

The Muslim Indo-Asian community was chosen due to the postulated powerful effect of religion toward organ donation in this group chose. In this study, I investigated further the important of religion on attitudes to organ donation in the UK Muslim Indo-Asian community.

Chapter 4

Research design and methods

4.1 Introduction

This chapter describes the methodology used to conduct this research study. The main aims of the study are clarified followed by a detailed discussion of the design and data analysis process. In addition, for further clarification, there will be detailed discussion about the rationale behind choosing this research design. Numbers and characteristics of individuals that participated in this research study will be described in the next chapter.

4.2 Aims

The formulations of clear aims before the beginning of a study of helps to direct the researcher's vision and should lead to a more economical use of resources (Sarantakos, 1998).

The main aim of the present study is to investigate factors that influence organ donation for transplantation among UK Muslim Indo-Asians. I shall attempt to identify those factors that enhance or inhibit organ donation among this population in order to provide data to help policy makers, hospital administrators, and transplantation professionals make informed choices about how to modify the donation system and structure appropriate interventions for the population under study. The study therefore looks at attitudes within the context of Islamic teaching and in the wider context of British transplant policy and practice.

The overall plan of the study is four fold:

(a) To investigate attitudes toward organ donation for transplantation held by UK Muslim Indo-Asians.

(b) To locate these attitudes in the broader Islamic perspective on health.

(c) To investigate opinions of health care professionals about the subjects.

(d) To examine (a), (b) and (c) in the context of policies, legislation and regulation of organ donation and transplantation in the UK.

4.3 Research study design

During the review of the literature, I found that the majority of the studies that investigated public attitudes used one or both of two different methods: either surveys or interviews. I shall briefly outline the principles I employed in selecting my research design.

Researchers should selectively, and appropriately, choose a research approach according to the nature of the problem and the information available about the phenomenon to be studied. Research can be approached from a variety of angles or methods. According to Denzin and Lincoln (2000), the choice of method depends on a number of factors, such as "the nature of the phenomenon to be studied, the maturity of the concept, constraints of the setting and the researcher's ability and agenda". Several considerations must be taken into account when deciding to adopt a research methodology. However, before describing the research design, it may be useful to define the difference between methodology and method.

Research methodology has been defined in various ways. It has been defined as a set of assumptions that accompany the research act, which embodies the entire research process. In another definition, "the researcher forms the methods of data collection and analyses within the theoretical framework". However, what is interesting here is how this term is defined by social scientists and health care professionals. There is agreement from many scientists that the term methodology means the general way in which the researchers approach a research topic (Hakim, 1987; Silverman, 1997; Taylor & Bogdan, 1998; Sarantakos, 1998; Bryman, 2001).

Research methodology can be classified in various ways. However, one of the most common distinctions is between two major methodologies: quantitative and qualitative. Researchers have long debated the relative value of each approach (Silverman, 2000). Although the difference between the two approaches is not the main subject to be discussed in this chapter, the next paragraphs provide a brief description of the differences between both methodologies, together with an outline of the factors that led to the methodological choices made in this research study.

As Patton (1990) argued, there is nothing better to differentiate between the qualitative and quantitative approaches than the different logic that underlines the sampling approach. He described that the difference between them is like "breadth and depth", which means that qualitative research is appropriate to study social issue in depth and detail, while quantitative research is used to measure the interaction between the variables.

It might be that it is possible to study only a few topics in details using a different perspective. Sarantakos (1998) argued that in quantitative methodology, researchers tend to employ highly structured techniques of data collection and analysis that allow quantification and the testing of hypotheses and, on the other hand, qualitative research uses less structured techniques. The differences between the two approaches have been extensively discussed in the literature. I have summarised the important features of each methodology in table 3.3.1.

	Qualitative	Quantitative
Nature of study	Inductive	Deductive
Research role	Active	Passive
Nature of reality	Subjective	Objective
Purpose	Reduction, control, precision	Discovery, description, understanding
Aims	Theory building	Theory testing
Approach	Dynamic	Static
Sampling	Theoretical	Random
Methods	Communication & observation	Instruments (e.g. questionnaire)
Sample size	Depends on saturation	Depends on population

Table 3.3.1 Differences between qualitative and quantitative methodology (Sarantakos, 1998)

Qualitative research typically produces a wealth of detailed data about a much smaller number of people. Alasuutari (1995) argued that the difference between the two research methods is that qualitative research provides more in-depth but sometimes "poorly representative data", whereas quantitative research gives data that are superficial but more "reliable".

Qualitative research can be used to explore a wide array of dimensions of the social world, including: the texture and weave of everyday life, the understandings, experiences and imaginings of the research sample, the ways that social processes work, and the significance of the meanings that they generate (Mason, 2002).

Because there are currently only limited studies on the issue of organ shortage among Muslims Indo-Asians, an exploratory multi-method qualitative approach was undertaken to enable the exploration of attitudes to organ transplantation in UK Muslim Indo-Asians. It has been argued that an exploratory study is recommended when there is little available on the subject in question (Sarantakos, 1998). The selection of qualitative research methodology for this research study was dictated by the nature of the phenomenon to be studied. Moreover, qualitative methodology was adapted to gain more in-depth information and develop understanding of the attitudes of Muslim Indo-Asians, which

would be difficult to convey quantitatively because there is no available recent information on which to base a quantitative approach.

In addition, qualitative research may also be used to generate information that may form the basis of subsequent quantitative work. Thus, findings from this research study might be appropriate in a situation where one needs first to identify the variable that might later be tested quantitatively. The research aimed to create new perspectives. Hammersley (1989) pointed out that qualitative research could provide a broader understanding of social phenomena rather than simply a relationship between variables.

Qualitative research then tends to take a developmental approach to the generation of ideas, concepts, hypothesis and theories. This approach has presented formally by Barney Glaser and Anselm Strauss, two sociologists who worked together on research about health care professionals interacting with dying patients. By using this approach, they identified a new phenomenon, which they called "open and closed awareness contexts" (Glaser & Strauss, 1966).

Glaser and Strauss discovered through the constant comparative analysis of the data that even though patients knew they were dying, they felt they could not express their feeling because of an unspoken taboo. Communication between staff and the dying patient is now better understood and practice has been greatly improved because of their work. Later, they developed their theory in the book called "The discovery of grounded theory" in 1967.

In their work they consistently argued for the inductive discovery of theory grounded in systematically analyzed data. Their inductive perspective stemmed in part from their "dissatisfaction" with the prevalent deductive practice of testing sociological theories. In the course of critiquing this prevailing dogmatic approach to theory testing, Glaser and Strauss provided a much broader concept of what social science researchers could and should do with their research time. Glaser and Strauss (1967) had three purposes: firstly, to offer the rationale for theory that was grounded; secondly, to suggest the logic for and

specifics of grounded theories; and thirdly, to "legitimise" qualitative research. Since the development of "grounded theory", many qualitative researchers have claimed the use of it to "legitimise their research approach" (Charmaz, 2000; Denzin & Lincoln, 2000).

As previously mentioned, the "grounded theory" approach to understanding, explaining and developing theory is "inductive". According to Charmaz (2000), this means that hypotheses and theories emerge from the data set while the data collection is in progress and after data analysis has commenced. The researchers examine the data for descriptions, patterns, and hypothesized relationships between phenomena, then return to the settings to collect data to further test the hypotheses. Therefore, the research is a process that builds theory inductively over a period, step by step. Almost all of qualitative research studies started without specific hypothesis, but rather, they produce them during the early stages of the research (Silverman, 1993).

Although it has been developed and principally used within the field of sociology, people in a variety of different disciplines have successfully employed "grounded theory" as well. However, it should be said that "grounded theory" is not so much a specific method or technique, but more as a style of doing qualitative analysis (Strauss, 1987).

Stern (1994) has highlighted several ways in which "grounded theory" differs from other methodologies: "1) the conceptual framework is generated from the data rather than from previous studies, although previous studies always influence the final outcome of the work; 2) the researcher attempts to discover dominant processes in the social scene rather than describing the unit under study; 3) every piece of data is compared with every other piece; 4) the collection of data may be modified according to the advancing theory; that is, false leads are dropped, or more penetrating questions are asked as seems necessary; 5) rather than following a series of linear steps, the investigator works within a matrix in which several research processes are in operation at once". In other words, the researcher examines data as they arrive and begins to code, categories, conceptualize, and to write his/her first thoughts about the research report almost from the beginning of the study.

The theoretical base for "grounded theory" was "symbolic interactionism". Glaser and Strauss (1967) pointed out that symbolic interactionism stresses that human behaviour was developed through interactions with others, through continuous processes of negotiation and renegotiation. Accordingly, Charmaz (2000) stated that proponents of the "grounded theory" methodology advocate that an approach which concerns itself with the meanings, definitions, and interpretations which are made by the subjects of the study has greater potential for depicting their society more accurately than methods which begin by preconceiving the society and its meaning.

It has been argued that the "grounded theory" method is ideally suited to investigation of those topics about which there is little prior knowledge which require that you approach data collection without a preconceived framework (Flick, 1998). In "grounded theory", reality is socially and culturally based, consequently the aim of using the "grounded theory" approach is to understand the nature of human behaviour by generating theories about social phenomena (Chenitz & Swanson, 1986).

Qualitative research which claims to be using "grounded theory", is always using a method as rigorous and systematic as that described by Glaser and Strauss. However, the emphasis on inductive processes and concept generation does seem a useful approach and this was adopted in the study. This process will encourage exploration of the data to discover the basic attitudes and social processes operating within my area of enquiry. In addition, since qualitative research generates large amounts of non-standard data which makes analysis problematic, the "grounded theory" method has been advocated as a way of handling these problems by an analysis process known as "coding", as I will explained later in this chapter.

My study was then influenced by the "grounded theory" approach but, given the limitation of time and resources, does not lay claim to being able to lead to a fully fledged "grounded theory" study.

4.4 Sampling strategies and settings

Appropriate sampling is a major issue for any kind of research. Sampling can be defined as a "process of selecting units (e.g. people) from a population of interest so that by studying the sample we may fairly generalize the results back to the population from which they were chosen" (Bryman, 2001).

In "grounded theory", participants are selected based on their knowledge of the topic and on the needs of the developing theory. This is called "theoretical sampling". Strauss and Corbin (1990) argued that theoretical sampling is unlike the sampling done in quantitative investigations. They stated that it could not be planned before embarking on a "grounded theory" study. The specific sampling decisions evolve during the research process itself. By "theoretical sampling" Glaser and Strauss (1967) mean the selecting of groups of categories for study on the basis of their relevance to the research.

The aim, in this research study, was to use theoretical sampling to develop more understanding of the phenomena under study and to make it more definitive and useful. Thus, the aim of this sampling is to refine the ideas and help to identify conceptual boundaries and pinpoint the fit and relevance of the categories.

Glaser (1992) argued that theoretical sampling translates in practical terms into two sampling events: an initial case is selected and, on the basis of the data analysis pertaining to that case and hence the emerging theory, additional cases are selected. He stressed that in theoretical sampling no one kind of data on categorization or technique for data collection is necessarily appropriate. Different kinds of data give the analyst different views or vantage points from which to understand a category and to develop its properties.

Certain researchers call theoretical sampling "purposeful sampling". According to Patton (1990), purposeful sampling is where the phenomenon is known to exist and the study participants are used to obtain maximum information and a full array of responses. Theoretical and purposeful samplings are often treated as synonyms. The only difference between the two procedures applies when the purpose behind purposeful sampling is not theoretically defined (Bryman & Cramer, 1990).

Qualitative researchers have few strict guidelines for when to stop the data collection process. The decision to stop sampling must take into account the research goals, the need to achieve depth of data sources, and the possibility of greater breadth through examination of a variety of sampling sites. The sample is based on the stage called "saturation of categories" (Glaser & Strauss, 1967). This is the conceptual elements of the theory and provides the means of classifying data. Flick (1998) stated that the data is said to be saturated when no additional information can be found to develop it further. He asserted that the researchers must then take the decision to discontinue collecting data and proceed to another research step.

Theoretical saturation according to Glaser and Strauss (1967) occurs after many rounds of coding where no new categories emerge from the process. Once this point is reached, further data collection is no longer productive. According to Glaser and Strauss (1967), repeated data collection "only adds bulk" to the coded data and nothing to the result.

Flick (1998) stated that once theoretical saturation has occurred, the researcher can begin determining the relationships between data. He clarified that while it is determined by the judgment of the researcher, it occurs when further sampling fails to reveal additional categories, properties, or interrelationships.

Hence, sampling is guided by theoretical development, which becomes progressively more focused. However, sample size may be small or large, depending on the type of research questions, material and time resources, as well as on the number of researchers (Patton, 1990). Generally, qualitative sampling consists of small sampling units studied in depth.

4.4.1 Study setting

Indo-Asian population of the UK can be divided into four main groups based on religion: Buddhism, Hinduism, Islam, and Sikhism. I studied a sample of Muslim Indo-Asian community in West London because of the increasing of number of patients suffering from of end stage renal failure in the context of disproportionately fewer organ donations. There are various reasons behind this selection. I specifically chose Muslims on account of several studies that were conducted in the UK to investigate the attitudes of Indo-Asians toward organ donation which showed that Muslims in particular are unsure about their attitude in comparison with Hindus or Sikhs.

Furthermore, as Darr and Randhawa (1999) pointed out, Indo-Asians communities in UK are culturally and religiously "extremely heterogeneous". I felt that maximum information would be obtained if the group under study was as homogenous as possible. In direct contrast to maximum variation sampling is the strategy of picking a small homogeneous sample. A homogeneous sample as defined by Patton (1990) as a group of individuals who belong to the same subculture or have similar characteristics. The purpose here is to describe some particular subgroup in-depth.

The first problem that I faced was to determine the location of the study. I decided to seek the help of a number of experts who were working closely with this community, including the Renal Transplant Liaison Nurse for the Asian community at the Hammersmith Hospital and Dr Aziz Sheikh, Training Fellow, Primary Care, Imperial College School of Medicine and author of "Caring for Muslim Patients", published by The Muslim Council of Britain (MCB). We came to the conclusion that a good place to conduct this research study would be in Islamic Centres. I used the Muslim Directory, which is like a Yellow Pages for the Muslim community, to identify all of the Islamic Centres in West London.

There are more than fifteen such Islamic centres in West London. My selection was based on the following criteria: location in an area inhabited mainly by Indo-Asians, a building with large capacity (with potential space for more than 1000 congregants at the same time), and a centre which provides a wide range of services, such as educational classes (for children and adults), sports and social activities, facilities for women, and family counselling, and which conducted five daily prayer services and Friday prayers, funeral services, and other community services. These criteria meant that each Centre was likely to expose me to as wide a range as possible of individuals from within the West London Muslim Indo-Asian community.

The selection identified three Islamic Centres: (1) the Abubaker Mosque Islamic Educational and Recreational Institute (Southall), (2) the Central Jamia Masjid and Islamic Centre (Southall) and (3) the Hounslow Jamia Masjid and Islamic Centre (Hounslow). Work was carried out in the first centre and repeated in the other centres to test and validate initial findings.

By the time the initial field study was completed, it become clear that it was necessary to address some issues relating to organ donation and transplantation with relevant health care professionals. Therefore, the next step was to identify samples of professionals who worked or did research in the field of organ donation in the Indo-Asian community.

Professionals who were working with Indo-Asians patients were selected from four hospitals: the Hammersmith Hospital, St Mary's Hospital, the Royal Free Hospital, and Charing Cross Hospital. Selected individuals at these Hospitals were invited to participate by an E-mail outlining the purpose of the study. This was followed-up by telephone. Meanwhile, selected Muslim leaders were approached because they are responsible for addressing this matter and educating Muslim communities in the UK.

4.5 Data collection methods

One important way to strengthen study design is to use several different kinds of methods for data collection. By "method", I mean specific research techniques and instruments. As has been emphasised above, data collection, sampling and analysis all occur simultaneously as the study progresses and sampling and further data collection are based on the emerging theory. Two key processes highlight this phase of analysis: coding and categorizing (Stern, 1980). I will talk about each later in this chapter.

4.5.1 Multiple methods of data collection

The use of multiple data sources is intended to enhance construct validity and reliability. Patton (1990) stressed that it is possible to achieve the use of multiple methods within a qualitative inquiry strategy by combining different kinds of qualitative methods, mixing purposeful samples and including multiple perspectives. In addition, he stated that researchers could use different methods to confirm the findings generated through one particular method by another. This process is called "triangulation".

Triangulation has been defined as the combination of two or more theories, data sources, methods or investigators in one study of a single phenomenon (Patton, 1990; Sarantakos, 1998). The use of triangulation for the purpose of confirmation has necessitated the identification of data collection instruments or techniques whose strengths and weaknesses are known, and then counterbalancing them to minimise threats to validity (Denzin & Lincoln, 2000). Denzin and Lincoln introduced the idea of multiple strategies of triangulation as a way to confirm the accuracy of one's data set. They were the first to postulate that triangulation involves varieties of data, investigators, theories and methodologies. They believed that the ultimate purpose of such an approach is to overcome the intrinsic bias of single-method, single-observer, and single-theory studies. While Denzin and Lincoln extended the triangulation metaphor beyond a measurement focus, they supported the view that the fundamental purpose of triangulation is to confirm the researcher's results and conclusions.

Some researchers have also identified another purpose served by combining data collection strategies. Fielding and Fielding (1986) advocated that the combining of multiple theories and methods in a single study in order to add depth and breadth of understanding to the phenomenon. They believed that when triangulation is conceptualised as a means of achieving validity, it has only limited relevance for qualitative researchers, who are seldom concerned with the measurement of a discrete concept.

Flick (1998) argued that the use of multiple methods is a strategy of validation which can be best understood as a strategy that adds "rigor, breadth, complexity, richness, and depth" to any research. That was strongly supported by Silverman (2000), who stressed that triangulation plays a critical role in qualitative research to improve the reliability as well as the validity of a single method.

Schatzman and Strauss (1973) maintained that the choice of research methods should be consistent with the nature of questions asked, and that the research aims of the study required a combination strategy, which would illuminate both "personal perceptions and social processes". The important issue here, as Silverman (1993) pointed out, is that whatever method or combination of methods is used, the researcher must clearly describe and justify each stage of the research process in order to preserve the integrity and rigour of the research.

The researcher himself plays an important role in conducting research. Glaser and Strauss (1967) referred to what they call the "theoretical sensitivity" of the researcher. According to Strauss and Corbin (1990), this concept evaluates a "researcher's skill" and his/her "readiness" to attempt a qualitative inquiry it is refers to a personal characteristic of the researcher which includes an awareness of the subtleties of meaning of data which refers. As such, to the attribute of having insight, the ability to give meaning to data, the capacity to understand, and the capability to separate the pertinent from the irrelevant.

Moreover, Eisner (1991) stated that the credibility of a qualitative research report relies heavily on the confidence readers have in the researcher's ability to be sensitive to the data and to make appropriate decisions in the field.

In addition, effective theoretical development is greatly enhanced by theoretical sensitivity. This theoretical sensitivity consists of professional or disciplinary knowledge, as well as both research and personal experience that the researcher brings to his or her inquiry (Strauss and Corbin, 1998).

Strauss and Corbin (1998) argued that a rich source of theoretical sensitivity can be gained from a careful, selective sampling of the literature. They stated that relevant literature can be scrutinized and the concepts compared as data. However, they stressed that the researchers who use those conceptual roots as sensitizing concepts to alert them to central issues need to remember that, in using "grounded theory" methodology, literature is only used as data to explain, not derived the theory.

Fieldwork is the central activity of qualitative inquiry. Qualitative approaches emphasize the importance of getting close to the people and situations being studied in order to understand personally the realities and minutiae of daily life, shared experience and confidentiality. This makes possible description and understanding of both externally observable behaviours and internal state (Patton, 1990).

There are many different methods of qualitative research. Data are generally collected through interviews, observation and other fieldwork techniques (Denzin & Lincoln, 2000).

In order to meet the objectives of this research study, it was decided to use four methods: participant observation, focus group discussions, in-depth individual interview, and documentary analysis. The integration of different methods here explores different parts of the phenomenon under study and clarifies how the parts are linked at the levels of knowledge and explanation.

The following is a detailed discussion of each of the four techniques of data collection used in this research study.

4.5.1.1 Participant observation

It has been argued that human behaviour is significantly influenced by the setting in which it occurs. One cannot understand human behaviour without understanding the framework within which subjects interpret their thoughts, feelings and actions. In general, observation has been characterised as the fundamental base of all research methods in the social and behavioural sciences (Rossman & Rallis, 1998). It is a typical data collection method used in qualitative research (Glaser & Strauss, 1967). The classic form of data collection in naturalistic or field research is observation of participants in the context of a natural setting.

This method was chosen, as it has often been the chosen method to understand another culture (Silverman, 1993). Observational data are used for the purpose of the description of settings, activities, people, and the meanings of what is observed from the perspective of the participants. It can lead to deeper understanding than interviews alone, because it provides knowledge of the context in which events occur, and may enable the researcher to see things that participants themselves are not aware of, or that they are unwilling to discuss (Patton, 1990).

Moreover, Marshall and Rossman (1989) stated that observation entails the systemic description of events, behaviour, and artefacts in the social setting chosen for the study. They assumed that behaviour is purposive and expressive of deeper values and beliefs. Observation can range from highly structured, detailed notation of behaviour to more diffuse, ambiguous descriptions of events and behaviour.

As little was known about the area and Indo-Asians community, more time was given at the beginning to observing people in each area and the activities in the centres.
There are several observation strategies available. In some cases it may be possible and desirable for the researcher to watch from outside, without being observed himself.

However, participant observation, which I decided to do, is a special form of observation and demands first hand involvement in the social activities chosen for study. It adds breadth to research and provides answers to contextual questions, which cannot be answered by any other method (Patton, 1990).

The primary purpose is to observe the participant in as natural a setting as possible. Consequently, it is desirable to obtain an accurate, detailed description of the setting. It is also essential to ensure that the setting is minimally disrupted or altered by the presence of the researcher. Yin (1994) suggested that the main strengths of participant observation lie in its ability to capture reality and context and its ability to generate full insights into interpersonal behaviour and motives. Against these strengths, he suggested the weaknesses lies in its potential for selectivity, reflexivity and bias due to the researcher's manipulation of events.

I found that participant observation was particularly useful as a way of learning about Muslim Indo-Asian social life, the ways in which they relate to each other and the ideas to which they appeal in order to make sense of their community. Therefore, since the Muslim Indo-Asian community is unfamiliar to me, and given the value of the method, it was chosen as an empirical method in this research study.

In an order to become fully engaged in experiencing the setting under study, while at the same time trying to understand the setting through personal experience, observations and talking with other participants about what is happening, an effort was made to share as intimately as possible in the life and activities of the setting under study. The purpose of such participation is to develop an insider's view of how they communicate in the community.

Immersion in the setting offered a realistic experience of the participants` points of view. Patton (1990) argued that to develop a better understanding of a society, the researchers should immerse themselves in it, learning, as far as possible, to think, see, feel and sometimes act as a member of its culture but at the same time remain apart.

Taylor and Bogdan (1998) argued that the researcher spends a considerable amount of time in the setting, learning about daily life. They argued that, although this method takes more time to generate in-depth information about culture or subculture and to try to avoid disturbances and potential biases caused by the researchers` own beliefs, observation is less disruptive and more unobtrusive than interviewing. They stated that it does not just involve observing the situation, but also listening to the people under study.

However, the major concern was about the validity and reliability of observational data because of the effects of the observer on what was being observed. The basic notion here is that people may behave quite differently when they know they are being observed compared with how they would behave if they were not aware of being observed. Thus, the argument goes, covert observations are more likely to capture what is really happening than are overt observations (Patton, 1990).

The fieldwork was undertaken first in the Abubaker Islamic Educational and Recreational Institute, Southall. A visit was made to the Centre and introductions took place with the General Secretary and the Imam. The purpose of the study was explained to them in order to facilitate the cooperation. There were most welcoming and provided all the necessary help required. The activities in the Centre begin with dawn prayers, which is at the time of sunrise.

The Institute is rather quiet in the morning. Accordingly, the decision was taken to start the observation period from noon for a period of approximately ten hours daily, during which most of the activities take place. The same approach was adopted in the other two Centres used in the research study.

During the fieldwork, the guidelines for fieldwork given by Patton (1990) were followed. These are: "Be descriptive in taking field notes, gather a variety of information from different perspectives, gathering different kind of data, use quotations, key information and be aware of, and sensitive to, the different stages of fieldwork, build trust and rapport at the entry stage, stay alert, disciplined, and focus on pulling together a useful synthesis,

take detailed field notes, be involved as possible, separate description from interpretation, and include your own experience".

Field researchers rely most heavily on the use of field notes, which are running descriptions of settings, people, activities, and sounds. Acknowledging the difficulty of writing extensive field notes during an observation, Lofland and Lofland (1995) recommend jotting down notes that will serve as a memory aid when full field notes are constructed. They stressed that this should happen as soon after observation as possible, preferably the same day. This was the approach I took in addition to field notes.

As the purpose of observational data in this study was to describe the setting that was observed, the activities that took place in that setting, the people who participate in these activities, and the meaning of what was observed from the perspective of those observed, I usually recorded all observations on audio-tape. Simultaneously field strategy combines document analysis, interviewing of respondents such as informants and direct participants observation.

4.5.1.2 Focus group discussion

Focus group discussion has been described by Kreuger (1988), as "a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment". The use of focus group discussions is gaining in popularity as a method of qualitative data collection amongst social scientists and health care professionals (Fontana & Frey, 1994).

Focus group discussions are now used particularly in exploratory studies and the evaluation of health care services. The number of citations of focus groups in health research has increased exponentially since the eighties (Basch, 1987). In the UK, a recent collection of papers on focus group research by social scientists is concerned with "Developing Focus Group Research" (Barbour & Kitzinger, 1999).

This method was used, because it can obtain data about feelings and opinions from a small group of participants on a given problem, experience, services or other phenomena (Morgan, 1997). It allows for the gathering of data or development of a perspective on the research phenomenon not always available through other research methods. A focus group's discussion also allows the researcher to guide the interaction of participants simultaneously, and therefore guide data collection at the same time.

This was supported by Kitzinger (1995), who found that they were appropriate when researching sensitive issues, and particularly so when researching stigmatised conditions. Additional advantages are that this process is inexpensive, data-rich and elaborate (Morgan, 1997). All definitions of focus group discussions consider the use of interaction among participants as a way of accessing data that would not emerge if other methods were used.

Group members can be asked about issues in personal interviews and the reality may be similar to what would be obtained in a focus group discussion. In fact, in a personal, face-to-face interview, the respondent can describe his/her group and its culture, but in a group situation, that culture is actually present in the sense that when they speak to one another, members of a cultural group can use insider terms and concepts (Alasuutari, 1995).

However, Morgan (1988) argued that one of weaknesses of focus group discussions is that the researcher has more difficulty managing the debate and less control than in a one-to-one interview. In addition, as group members interact throughout the interview, one or two individuals may dominate the discussion and influence the outcome, or perhaps even introduce bias, as the other members may become passive and compliant (Morgan, 1997).

Additional criticisms exist about the use of focus groups. One important issue is the reliance placed on the skill of the moderator in facilitating the group process and interaction. The moderator requires skills in encouraging equal participation, re-focusing the interview if necessary and pulling participants back together if the interview breaks

down into two or more discussions. Further, high risk issues can be perceived as threatening, particularly if they involve disclosing personal viewpoints or behaviour. Potential problems with this method are group dynamics interfering with the research process and as stated above, one or two individuals dominating the interview (Fontana & Frey, 1994).

Another disadvantage of focus groups discussion is that participants can modify each other's responses. However, focus group discussion can empower research participants because they become part of the process of analysis (Morgan, 1997). Previous experience of group facilitation suggested that these problems can be easily managed, thus enabling the clarification of conflicts between participants and the reasons for differing views.

On the positive side, one of the major advantages of adopting focus groups as a method of data collection in this research study resulted from the group process and the interaction of group members. The synergism created from this interaction is considered significant for the stimulation of new ideas and discussion (Morgan, 1993). Basch (1987) argued that focus group discussions are also advantageous in dealing with complex issues. This approach to data collection provides the opportunity to collect in-depth information about complex topics in a relatively short period, particularly since the aim of focus groups is not necessarily to achieve consensus amongst group members (Morgan, 1995).

The main strength is the production of data thorough social interaction. The dynamic interaction stimulates the thoughts of participants and reminds them of their own feelings about the research topic. According to Morgan (1997), it is a highly efficient qualitative data collection technique provided some quality controls on data collection are in place. All the participants have the opportunity to ask questions, and these will produce more ideas than individual interviews. Furthermore, it allows the researcher to access the attitudes and values of informants while observing the interaction of the participants.

In selecting participants for a focus group, relatively selected homogeneous groups were chosen because the goal in using this technique was to encourage individuals to share their ideas and perceptions. Focus group discussions are typically based on homogeneous groups. Because the purpose in using a focus group is to produce self-disclosure, homogeneity is seen as reducing perceived risk to the informants. For this reason, several focus groups are generally used within a research project to increase the range of beliefs and values that will be represented in the population under study, with the aim of using heterogeneity between the groups (Morgan, 1993).

In a focus group, the researcher brings together between six and nine users to discuss issues and concerns. The group typically lasts about two hours and is run by a moderator who maintains the group's focus. Merton and King (1990) suggested a spatial arrangement of a circle or semi-circle as this seems to be the most successful seating arrangement. The group interviews should have a clearly identified agenda otherwise they might deteriorate into vague and chaotic discussions. These principles were adhered to in the focus groups run in this research study.

Three focus group discussions in each Centre (i.e. a total of nine groups) provided opportunities for participants to raise the issue of organ donation for transplantation with other members of the group. The focus group discussions were advertised on the Centre's advertisement boards, after prayers, and at classes to encourage people to participate. The individual who acted as the initial point of contact was invited to participate in the group discussion. Participants were categorised according to age and sex. The participants in each Centre were divided into three groups. One group was for males over sixty years old and the other two groups were for adult males and females whose ages ranged from eighteen to fifty-nine years old.

It was impossible to have a female senior group because this group has no dedicated programmes at which to recruit them. Single-sex groups were used to conform to the rules and policies of the Centres. In addition, this helped to eliminate any inhibitions about discussing personal issues. A lecture room was booked and prepared for each discussion group.

To minimise the phenomenon of group thinking, participants were asked to write down in a few sentences at the start of each session what they knew about organ donation and transplantation in the UK. Papers and pencils were provided for every participant. The researcher moderated the discussions and research objectives were explained at the start of each session, and ground rules about confidentiality and respect for others` opinions were agreed.

Each session was held in a quiet room with comfortable seating in a circle and lasted for approximately 120 minutes. However, some male group discussion was held in the prayer hall of the Centres, sitting on the floor, as this seems to be preferred by the participants. Permission to tape-record the discussion was verbally obtained and brief written notes were taken during discussions.

It was found useful to have a topic guide based on information from personal experience and the findings of the studies in the literature review during the discussions in focus groups and interviews. The following areas were included on as a topic guide list through individual and groups discussions: awareness of existing organ donation and transplantation activities, willingness to donate one's organs and those of relatives, attitudes regarding the issue of organ donation for transplantation, and the appropriate procedures for organ procurement. The questions were open-ended and words that might influence answers were avoided, to give the participants the opportunity to choose their own terms when answering questions.

A supportive and relaxed environment encouraged participants to express their opinions and experiences. By the end of session, it became clear that saturation point had been reached as no new information was emerging. There was a period at the end of each session which gave the participants time to talk freely, ask questions and debrief.

Field notes from these group discussions were maintained, which were transcribed and coded on to index cards. Transcription can be much more difficult because people's voices vary, and the distance they sit from the microphone influences the clarity of individuals` contributions. However, to control the discipline and avoid interruption, the audiotape recorder was moved from one to another for a purpose of controlling the group and avoiding interruptions.

4.5.1.3 In-depth individual interviews

The one-to-one individual interview is one of the most commonly employed qualitative methods of sociological research. It is a way of generating empirical data about social experience through asking people to talk about their lives and experiences (Morse and Field, 1995). Accordingly, interviews are special forms of conversation, which may vary from highly structured, standardised, qualitatively oriented survey interviews, to semi-formal guided conversation and free flowing exchanges of information. People's knowledge, views, understandings, interpretations, experiences, and interactions are meaningful properties of the social reality, which can be explored by interview (Denzin & Lincoln, 2000).

It has been argued that it is useful to have a combination of observing and informal interviewing. However, it is more economical than observation. The broader societal context may explain the qualitative researcher's temptation to use methods such as the interview.

Qualitative interviews may be used either as the primary strategy for data collection, or in conjunction with observation, document analysis, or other techniques. Patton (1990) described three types of qualitative interviewing: "1) informal, conversational interviews; 2) semi-structured interviews; and 3) standardized, open-ended interviews". However, there are many types of interviews, as described by Bryman (2001), which are not relevant for the purposes of this study.

I decided to use in-depth interviews for the purpose of this research study. Bryman (2001) suggested that in the in-depth interview the researchers can use both semi-structured and unstructured interviewing. Accordingly, a guide to open-ended questions that allowed for individual variation was prepared.

Lofland and Lofland (1995) stated that an interview guide is a list of questions or general topics that the interviewer wants to explore during each interview. They argued that, although it is prepared to ensure that basically the same information is obtained from each person, there are no predetermined responses, and in semi-structured interviews the interviewer is free to probe and explore within these predetermined inquiry areas.

Interview guides ensure optimal use of limited interview time; they make interviewing multiple subjects more systematic and comprehensive; and they help to keep interactions focused. In keeping with the flexible nature of qualitative research designs, interview guides can be modified over time to focus attention on areas of particular importance, or to exclude questions the researcher has found to be unproductive for the goals of the research (Lofland & Lofland, 1995).

In this research study, two groups of subjects were interviewed: members of the public from Muslim Indo-Asian community, and health care professionals. Members of the public were interviewed in the Islamic Centres. The key persons in each Centre helped to recruit participants. Each participant was interviewed individually in a quiet room chosen to avoid any disturbance. The interviewees were given detailed explanations of

the objectives of the interview and how long it would take. The interviews, which lasted for between forty and eighty minutes were recorded for the purpose of later analysis.

The professional interviews were carried out with researchers interested in the issue of the organ shortage among the Indo-Asian community. They included health care specialists in organ donation and transplantation working in various NHS sites in West London, North Thames Transplant Co-ordinators, UK Transplant officials, and the Department of Health officials. In addition, people who are interested in the subject of the attitude of Indo-Asians toward organ donation and Muslim scholars were interviewed. Appointments were arranged by E-mail and by phone. The interviews took place in the subjects` offices during working hours. Permission was obtained for audiotape recording and the interview lasted between thirty and sixty minutes.

4.5.1.4 Documentary analysis

Another source of information that can be invaluable to qualitative researchers comes from the analysis of documents. Such documents might include official records, letters, newspaper accounts, diaries, and reports, as well as published data (Sarantakos, 1998).

In this research study, I found that most of the Muslim participants mentioned verses from the *Qur'an* and Islamic tradition. Thus I found it appropriate to review relevant documents to understand particularly the issue of organ donation in Islam and health in general. I reviewed the *Qur'an* and other document relevant to the Prophetic tradition for information about organ donation and health.

Also, I reviewed the *fatwa* and documents on Islamic *Shariah* as required. Furthermore, I analysed Islamic books and documents in the field of health in general and organ donation in particular. I found most of these books and articles were available in the libraries of the Islamic Centres that I visited, the Regent's Park Islamic Centre, and the Muslim College.

Also, I reviewed UK materials used in campaigns to Indo-Asians community to enhance organ donation. Dr Peter Doyle, Senior Medical Officer at the Department of Health

provided these. Furthermore, extensive analysis of law and policies of organ donation and transplantations was also undertaken. There was available through Her Majesty's Stationery Office.

4.5.2 Data recording

A basic decision as I began data gathering was how to record the data. Whether one relies on written notes or an audiotape recorder appears to be largely a matter of personal preference. For instance, Patton (1990) said that an audiotape recorder is "indispensable". On the other hand, Lincoln and Guba (1985) do not recommend recording except for "unusual reasons". Lincoln and Guba based their recommendation on the intrusiveness of recording devices and the possibility of technical failure. Recordings have the advantage of capturing data more faithfully than hurriedly written notes might, and can make it easier for the researcher to focus on the interview.

It has been suggested that taking key-word notes during the study and converting them to themes afterwards is desirable approach. It has also been suggested that audiotape record the interviews and checking notes against the tape recording is valuable. This would not be as time-consuming as full transcripts and it would do the job as well. I decided to audio-tape all interviews as well as taking notes or, as Strauss and Corbin (1990) described them, "theoretical memos".

According to Strauss and Corbin (1990), theoretical memos are short documents that one writes to oneself as one proceeds through the analysis of a body of data. Equally important is the theoretical note. A theoretical memo is any additional remark one records as to how something in the text or codes relates to the data. The final theory and report is typically the integration of several theoretical memos. Writing theoretical memos allows a researcher to think theoretically without the pressure of working on paper. Throughout this process of theory development, one major process dominates the research process - memo writing.

Charmaz (1990) stated that memo writing takes place throughout the research process, starting with the first interview or observation. Through memo-writing the researcher moves directly into analysis of the data. Memos are written elaboration of ideas about the data and the coded categories. Charmaz (1994) asserted that the memo informs what the code is about and provides the pivotal step of breaking the categories into components and elaborating the codes.

Accordingly, it is imperative to interrupt coding for writing a memo when an idea occurs, so that the idea is not lost. Writing memos accomplishes at least five important aspects of generating theory (Glaser, 1978): "1) it raises the data to a conceptualization level, 2) it develops the properties of each category which begins to define it operationally, 3) it presents hypotheses about connections between categories and/or properties, 4) it begins to integrate these connections with clusters of other categories to generate the theory, and 5) it begins to locate the emerging theory with other theories with potentially more or less relevance".

At the end of the process, I sorted and integrated the memos. Sorting memos as defined by Strauss and Corbin (1990), simply means putting those that elucidate the same category together in order to clarify its dimensions and to distinguish it from other categories. Finally, immediately after each interview, I listened to the transcribed audiotape material and compared it with the information generated by integrating the memos. This also revealed the relationship between the categories.

Throughout the process of theoretical coding, memos and constant comparison, the core variables emerged. The stage of completion was reached when all the categories appear saturated, i.e. when no new information was being received which further explained that particular aspect of the emerging hypotheses, as Glaser (1992) said when a researcher stopped hearing anything new.

4.6 Data analysis

Qualitative analysis requires some creativity, for the challenge is to place data into logical, meaningful categories, to examine them in a holistic fashion, and to find a way to communicate this interpretation to others (Patton, 1990). As I indicated early in this chapter, data analysis is central to grounded theory-based research. As data began to emerge, this guided further data collection and the discussion became more focused. Data were analyzed using a systematic set of procedures to develop a substantive theory of the phenomenon.

Data analysis begins with the first observation and interview, which leads to the next and so on. Data emerging from the study were analysed simultaneously while the study took place. All audiotapes and memos were transcribed and codes were made next to phrases, words or comments in the text from the beginning. Transcripts of audiotape are an increasingly important part of qualitative research. Transcripts of such recordings, based on standardised conventions, provide an excellent record of naturally occurring interactions. Compared to field notes, observational data, recordings and transcripts can offer a highly reliable record to which researchers can return as they develop new hypotheses (Silverman, 1993).

The data were read through several times. Therefore, there was a constant interplay between the researcher and the data. Each word, line and paragraph was examined thoroughly to discover and label the phenomena being described.

Strauss and Corbin (1990) called this process of examining and interoperating the collected data in detail as a "microanalysis". They stressed that line-by-line analysis is necessary at the beginning of a study to generate initial categories and to suggest relationships among categories. Doing line-by-line coding is especially important at the beginning of a study because it enables the analyst to generate categories quickly and to develop those categorise through further sampling along the dimensions of a category's general properties, the process of theoretical sampling I discussed above.

All the facts perceived as being important were labelled and a list of relevant concepts was revealed. As mentioned before, the aim is to identify core categories, by grouping coded concepts under a single cover term and label.

Each label was then compared with every other label and assigned to categories according to obvious similarities. Labels are thus drawn together and grouped in order to represent the tentative categorisation. These categories are used to explain the properties of the phenomena under study.

Coding can be done very formally and systematically or quite informally. In "grounded theory" it is normally done quite informally. That was the case in this research study. Coding is a process of simultaneously reducing the data by dividing it into units of analysis and coding each unit. Two key processes highlighted this phase of analysis: coding and categorizing (Stern, 1994). Coding, the initial phase of the analytical method, is simply the process of categorizing and sorting data. Codes serve as devices to label, separate, compile, and organize data (Charmaz, 1994). I began by looking for processes. As the data were collected, I applied a system of open coding.

Glaser (1978) advocated that the coding processes should be developed in two phases: the initial coding followed by focused coding. In the initial phase, researchers look for what they could define and discover about the available data. Strauss and Corbin (1990) stated that the development of such codes during this initial coding phase serves to summarise, synthesise, and sort the many observations made of the data. However, it is important to emphasise that I made codes fit the data, rather than force the data into codes, the objective being to identify the processes in the data.

Categories were developed from the coded data in the second phase by what Glaser (1992) called focused coding. According to him, the purpose of focused coding is to build and clarify a category by examining all the data it covers and variations from it. In focused coding, the researcher takes a limited set of codes that were developed in the initial phase and applies them to large amounts of data.

Codes were then sorted into categories and redefined into further focused categories from which constraints and theory emerged. Sometimes the actual words used by the participants were used to name the concepts. This enabled the researcher to avoid assigning his meaning to the phenomena and ensured that the concepts derived were those of the participants themselves. The concepts were written in the margin of the data-coding sheet and combined with any relevant field notes or researcher deductive reasoning. The process also involved making comparisons when identifying, clarifying, categorising and differentiating concepts (Glaser, 1992).

Data analysis in this research study started with identifying, naming, categorizing and describing phenomena found in the text. Initial coding began immediately after each method of comparative analysis and involved transcribing each discussion and interview. These were then analysed using the comparative analysis method devised by Glaser and Strauss (1967). Whereas open coding fractures the data into concepts and categories, axial coding puts those data back together in new ways by making links between a category and its sub-categories. Although axial coding differs in purpose from open coding, these are not necessarily sequential analytical steps, no more than labelling is distinct from open coding. Thus, axial coding, which means the process of relating codes to each other, refers to the process of developing main categories and their sub-categories.

4.7 Ethical considerations

In any research study, the researcher must consider the legal and ethical responsibilities associated with the project. Oppenheim (1996) stressed that the basic ethical principle is that no respondent should be exposed to harm as a result of his or her participation in the research. However, the difficulty in obtaining informed consent in qualitative studies is well documented. Eisner (1991) argued that truly informed consent is impossible in such studies because events in the field cannot be anticipated and researchers therefore cannot inform participants what to expect. Furthermore, it is difficult to predict the exact time commitment involved for participants in qualitative studies. Homan (1991) argued that in qualitative research it might be impossible to give a clear statement to potential participants at the outset about the anticipated outcomes and benefits of the study.

It was also difficult to determine which group if any, had the authority to consider the ethical issues associated with this research study. Since one of my supervisors, Dr Anthony Warrens, has an honorary contact with the Hammersmith Hospitals NHS Trust, we approached the Chairman of the Hammersmith Hospital Research Ethics Committee to take advice in this matter. He felt his committee was in a position to consider this research study and, after due process, this committee granted ethical permission to proceed.

Access to organisations to undertake participant observation is usually granted by requesting permission from those in charge, who are usually referred to as "gatekeepers". One does not need to negotiate access with gatekeepers to a public setting, so strategies were developed to research the settings and to facilitate interaction with informants. This removes the need to explain the research procedure and interests to gatekeepers or informants, which can be a difficult and sensitive task.

I made sure that each participant understood the purpose of this study by giving information about the research relevant to the subject's decision to participate. Participation was voluntary and this was made clear to potential participants. Participants

in focus groups or interviews were informed that they could leave the group at any time. Since gaining consent for a qualitative study is so difficult, it is generally accepted that oral consent is sufficient (Taylor & Bogdan, 1998). Actual participation was accepted as ongoing consent to participate in the research. The participants were informed that they could have access to the results of the study on request to the researcher.

An explanation was given of the aims and objectives of the study in general and the interview in particular, how it was to be conducted, why the respondent was chosen and for whom the data were being collected. The confidential nature of any information collected was stressed. Tapes were kept in a secure place and destroyed on completion of the research.

Part II

Findings

Chapter 5

The attitude of UK Muslim Indo-Asians towards organ donation and transplantation

5.1 Introduction

In this chapter, I will present data gathered and analysed from work undertaken in three Islamic Centres in West London: (1) the Islamic Educational and Recreational Institute (Southall), (2) the Central Jamia Masjid and Islamic Centre (Southall), and (3) the Jamia Masjid and Islamic Centre (Hounslow). These three centres can accommodate more than two thousand people at any one time. All use the term "*Jamia*" which means a congregational mosque in which the Friday prayers are performed. This will be discussed later in this chapter. Furthermore, in most parts of the Islamic world, the word *Jamia* means at once both mosque and school, even when they are separate buildings.

To begin with, I will describe my experience of participant observation in the three Centres. Then findings from focus groups discussions and individual interviews will be presented. To communicate much of the flavour of the interviews, I will use selected quotations. It is important to mention here that some of the participants spoke poor English and preferred Arabic or Urdu. Thus, most of the cited quotations have been either translated from another language or had their vocabulary or grammar changed into correct English. Interviews tended to include a significant amount of irrelevant material that has not been reproduced here.

5.2 Socio-demographic context of the participants

In total, one hundred and forty-one Muslim Indo-Asians of eighteen years or above participated in this study (100 male, 41 female). Sample size was deemed adequate when "saturation" was achieved, as explained in the previous chapter. The lower age threshold of 18 year was chosen using the lower age limit for donation allowed by law. The mean age of the men was 45 (range 18 to 73) and that of the women was 36 (range 18 to 55).

Forty-four males and twenty-two females participated in the focus groups discussions, while fifty-six males and nineteen females took part in the in-depth individual interviews. Eighty-four of the participants were married, forty-eight were single, nine were divorced, and two were widowed.

The participants can be divided into two main distinct groups of immigrants: those who came on their own or with a partner as first generation immigrants and have been in Britain for 50–60 years (75 participants), and those who were themselves born in the UK (65 participants). Older participants depended mainly on pensions and had a much lower formal educational level, with an educational attainment of less than graduate or even high school level, and had only a limited ability to read and write because they had come from villages or small towns where they received little or no education, and had subsequently worked in manual jobs. By contrast, young participants of both sexes were mainly university graduates and tended to be working in professional jobs. A few of the men were self-employed either working alone or employing just one or two other people.

Participants who were born in the UK and those who arrived as young children were likely to have obtained UK educational qualifications and to be fluent in English. Those who have arrived in middle age experienced more difficulty in speaking English.

Many participants were living with their grown children and their families in large extended families. There was considerable variation among female participants, especially those who were middle aged who were most likely to be married and staying at home as housewives. They were involved in the care of children and housework. Their busy lives at home and work left little time to engage on social activities outside. They tended to be living in nuclear families that lacked traditional social support and help with household tasks. The younger, employed females were future-oriented. They believed that they had to some degree succeeded in balancing two cultures.

5.3 Participant observations

Many areas of West London are considered as ethnic minority areas with large numbers of Indo-Asians. These include Southall, Hounslow, Acton, Shepherd's Bush, and Hayes. In these areas, the impact on the general appearance of the cultures of these communities is clear but the dominant culture in many areas is Indo-Asian. Most of these communities are South Indians. Following visits to all of these areas, Southall and Hounslow were selected for the fieldwork, being mainly Indo-Asian communities linked to India, Pakistan, Bangladesh, and Afghanistan, although there were also a few Arabs from Somalia and Iraq inhabiting these areas.

Although there are many Islamic Centres in these two areas, I selected three for further study according to the criteria outlined in chapter three. The two Centres in Southall were buildings adapted as Islamic Centres, while the one in Hounslow was built as a mosque according to Islamic architecture and has large car parking facilities. Since I found no important differences between the three Islamic Centres in which I worked, I will describe my observations for all in general. For ease of reference, the three Centres are designated as C1, C2, and C3.

5.3.1 Islamic Centres

Externally, the Centres have a *minaret,* which is a tall thin tower and a dome with a miniature crescent moon and star at the top, commonly used as a symbol for Islam. The two Centres in Southall are multilevel buildings as they were built as houses, while the one in Hounslow, which was purpose built, has a large prayer hall attached to a multilevel building.

The main entrance has wide doors and facilities for people with special needs. Just inside the entrance, a special rack is provided for shoes, which should be removed upon entering the Centre. This is because Muslims or any visitors are not allowed to wear shoes inside the Centre. Another rack for leaflets and newsletters stands in front of an announcement board used mainly for the Centre's activities as well as providing some messages for the public.

There is also a row of many taps where congregants can carry out ablution (ritual washing) or, in Arabic, *Wudo`a*. Muslims must wash their hands, face, arms and feet before praying. This is because a Muslim is expected to be in a state of purity when he/she visits the Centre. Tissues are provided for drying. Congregants wear modest clothes, mainly from their original countries. When they are talking to each other, they are expected to whisper. I was told that shouting or raising one's voice is not allowed inside the Centre, and using improper or foul language is unacceptable on account of the holiness of the place, which they consider the *House of Allah*. One of the Imams (C3) told me that Islamic Centres are:

> *Places for the inculcation of reverence, where individuals learn what is meant by piety and are thus prepared for a life of devotion to the Almighty.*

The main hall of each Centre is a bare room largely devoid of furniture, which is usually located on the ground flour and is used as a prayer hall. It is the most holy area in the Centre. It has many entrances and the floor is carpeted in a pattern that is designed to given enough space for each individual's prayer mat to allow a congregant to prostrate himself in his prayer. There are no seats, tables, pictures or statues. Muslims believe that there is no image for God or their Prophet. Also, it is forbidden to take pictures or make images inside the Centre.

When they come in to the prayer hall some congregants start praying by facing a niche in the wall that is known as the *Mihrab*, while others sit on the floor reading the *Qur'an* or exchanging conversation and holding beads. Prayer is offered whilst facing southeast in the direction of Mecca in the Kingdom of Saudi Arabia in which direction the niche is situated.

Along the walls around the hall there is a variety of Arabic texts of *Qur'anic* verses. A large clock and prayer schedule is on the wall near the niche. The rest of the wall is decorated with Islamic art. Prayer mats are also put on the walls for decoration. A drawing of a black cube-like building can be seen on one prayer mat used as a wall hanging. This the building is *Ka'aba* in Mecca in the direction of which Muslims face during prayer.

Muslims believe that they should perform an individual prayer as a greeting on entering the prayer hall. They kneel down and prostrate themselves repeated several times in the course of the prayer. They believe that the various postures, which consist of precise bodily positions, (standing, bowing, prostrating, and sitting), demonstrate their submission to Allah. The prayer is ended by turning their faces sideways and uttering a concluding phrase.

At the main prayer times, one of the congregants, a *Muezzin*, switches on the speakers which are located near the niche, and recites in Arabic the *Azan*. The congregants then arrange themselves standing in rows, with a leader standing in front. He is known as the *Imam*. He faces the niche and guides the congregants during congregational prayers. All Muslims assume the same posture as their Imam.

During prayer, the Imam recites verses from the *Qur'an*. Muslims stand together, kneel together, and sit together as indicated by the Imam's instructions. The number of congregants may range from ten to several hundreds. It appears as if they are taking a lesson in discipline, unity or obedience to the Imam. This was confirmed by one of the Imams who insisted that discipline is the external aspect of prayer.

The Imam usually serves as the religious leader who leads prayers and teaches Islam. Usually, he is hired by the mosque committee to meet the religious needs of the community. Most of them are brought over from abroad mainly from India and Pakistan and some of them have a formal Islamic education or hold a bachelor's degree from an overseas Islamic University. All of the Imams in the three Centres I studied are from India and Pakistan and have weak English. Also, all of them have been in the UK for only two to four years.

There is no ordained priesthood in Islam. Every Muslim can be an Imam; however, the most important thing is that the Imam should memorise the *Qur'an* very well. There is no special dress required for the Imam. In every Centre, there are executive committees or boards of directors serving as administrators. Those who are members are usually volunteers with jobs outside the mosque or seniors members of the community.

Muslims are pray five times a day. Each pray has a special name and is performed at particular times: between dawn and sunrise (*Fajr*), noon (*Zuhr*), mid-afternoon (*Asr*), sunset (*Maghrib*) and nightfall (*Isha*). These five daily prayers are obligatory and take five to ten minutes each. When I asked Imam (C2) whether praying in the mosque was a requirement for Muslims, he said:

> *While Muslims may pray almost anywhere, such as in offices, factories, universities, it is considered more meritorious when prayers are performed in the mosque together with other people: the Prophet Muhammad said that prayer in the mosque is 27 times more valuable than the one performed in the home.*

He stressed that Muslims need to perform prayer on time. At the typical Centre, the majority of the congregants are male. Although females are not permitted to pray in the mosque, they can attend the centre. They sit separately from the men. In each mosque there is a separate room for women at a higher level connected with the main prayer hall by headphones. Every Centre has a completely independent women's wing with its own

entrance. Apart from the usual prayer hall, ablution area, and a common room for the women to socialize and exchange views, the women's area also contains educational facilities.

Many Muslims come for the five daily prayers. However, the number and age of congregants depends on the time and the day. Many older people come to all prayers. Young people attend mostly *Maghrib* and stay until *Isha* prayer is finished (i.e. from sunset to nightfall) that because they work or are studying. However, during the weekend the Centre is full of people of different age groups (from infants to people over-eighty) who participate in many of the activities that will be mentioned later.

Besides the five daily obligatory prayers, there is a weekly Friday prayer, which must be offered in the mosque. Friday congregational worshiping is compulsory for Muslim men only. In most Islamic countries, Friday is a holiday rather than Sunday. It is not prescribed as a day of rest but rather one of obligatory worship. Work is permitted as usual before and after the time of Friday congregational prayer.

On Fridays, the congregants fill the Centre to its capacity. It is just like any other prayer; however, the Imam also preaches a sermon or *"khutba"* before the prayer beging. A *minbar*, the pulpit, from which the Friday speech is delivered, is located next to the niche, and is where the Imam stands. In this, he reminds the congregants of their accountability to God, to their families, and to others in society.

The sermon is delivered in Urdu because too many Muslims do not speak either Arabic (the official language for the sermon) or English. The congregants listen carefully to the sermon and remain silent until the prayer is finished. All ages and social classes of the community assemble for this event. The Islamic Centre not only plays a spiritual role in the life of the community, but is also involved in many social and educational aspects.

5.3.1.1 Education classes

Islam obliges Muslims to seek knowledge throughout their lives. From the very beginning, education has been obligatory for all Muslims, men and women, adults and children. Muhammad himself started the first school of Islam in the Medina mosque, where he gave lessons in the *Qur'an* and general ethics, known as *Sunnah* (this will be defined in the next chapter). Accordingly, Islamic Centres through the World devote much time and space to educational activities. A Muslim should learn Arabic to read the *Qur'an* and other Islamic texts, including many prayers. The association of the Islamic Centre with education has remained one of its main characteristics throughout Islamic history.

In the UK, the general education system does not have sufficient religious studies for many Muslims nor does it provide lessons in Arabic. So, Muslims felt that they should open schools to teach their children the basics of the Arabic language and Islamic studies, particularly the *Qur'an*. They tended to open small schools in mosques, which later became organised as basic classes for adults and children. This combination of functions led to introduction of the term, Islamic Centre. The school became an indispensable part of the Islamic Centre. Once established, it came to include libraries. All the Islamic Centres that I visited had extensive educational facilities.

Children from six up to fifteen years old sit or kneel at low benches with the *Qur'an*. In these classes boys and girls are separated. Each child goes to the front in turn to recite publicly verses they have learnt by heart during the week. They recite the *Qur'an* in Arabic in a special flowing rhythm. Qualified teachers who are usually from the community and specialists in their areas teach the children, although in some Centres the Imam assumes this role. Evening and weekend classes are offered for adult education.

In addition, there are daily lesson given by the Imam. The audiences sit in a circle and the Imam teaches them the *Qur'an*. This is called circle study and is known in Islam as "*Halaqa*". Sometimes, a visiting scholar gives the lesson. They can discuss any issue and relate it to Islam. These lectures usually take place in the evening, often on Fridays or during the weekend. There is almost no restriction in the choice of subjects.

As I said before, most of the Imams in the UK are immigrants from India or Pakistan, and often have difficulties speaking English. They have limited knowledge of the government, judicial, and economic systems and how the Health Service works in the UK. That became clear to me from their comments to their audience. However, despite all that, the Imam occupies a special position in the Muslim community who tend to show him great respect.

At a separate level, there is a hall arranged as a library and reading room. A library is an essential part of every Islamic Centre. It is situated on the first floor level and includes many Islamic references. It is designed to serve not only the congregants of that specific Centre, but also as fully-fledged community library equipped with literature and periodicals.

5.3.1.2 Social activities

The Islamic Centre works as a natural community centre for Muslims, which they find very convenient to use. For many senior citizens, it is a drop-in Centre and a place where they socialise with other community members. Muslims turn to the facilities of the Islamic Centre to seek help and advice in matters relating to their day-to-day life, particularly from the Imam. This is because many of them are immigrants living in an unfamiliar culture. The Centre is available for counselling where the Imams provide a full range of help and advice from an Islamic point of view. Issues that were commonly discussed include: matrimonial problems, the generation gap, and health issues. The Centre manages a welfare fund, which distributes charity to the poor. It also provides

funeral facilities according to Islamic teachings. The Islamic Centre in the UK is very different to similar institution in most Islamic countries.

Young Muslims also use the Centre for family and community celebrations, such as marriages, and sport activities. A regular stream of visitors from schools, colleges, universities, churches and other places visit the Centre. In recent years, the Islamic Centre has provide many activities for non-Muslims. They participate in various activities, such as organised seminars, programmes, exhibitions and open days for the general community, which helps to bind the communities together. Women are an integral part of the Centre's activities and they play an influential and active role. They have their own activities, which are separated from men.

In conclusion, Muslim communities have established themselves throughout the world. They have adapted many of the norms of their religion by establishing Islamic Centres. An Islamic Centre in the UK is an institution for the development of the intellectual, physical, social and cultural values of the Muslim community and attendance contributes to a Muslim's sense of religious identity. Commitment to religious beliefs is a strong factor influencing the preservation of Islamic identity. In addition, the Islamic Centre plays an important part in education, serving as a meeting place where people discuss their problems and try to find solutions and provide education for all sections of the community in order to allow members to live in the British multi-cultural society.

5.4 Factors influencing the attitude of Muslim Indo-Asian

The objective of this research study was to determine the understanding of organ donation within the Muslim Indo-Asian community. It was interested that an overwhelming number of participants were aware of both living and cadaveric organ donation for transplantation. However, they were not aware of the details of the process and its benefits. Although most of participants considered that organ transplantation save lives, the majority of them were opposed to it, particularly in the UK. Virtually all participants agreed that organ donation might allow something positive to come from a

person's death. They agreed unanimously with blood donation. Indeed, many thought that blood is the only thing that Muslims are allowed in Islam to donate.

> *The only donation allowed in Islam is blood donation.*
>
> (Male, 29, I, C2)

When describing organ donation, participants used expressions taken from non-medical sources. Their knowledge was gleaned principally from television, radio, and the press. However, their attitudes reflected not only their knowledge on the subject, but also the reputation of the National Health System (NHS) in the United Kingdom in their eyes. Negative attitudes about donation arose from mistrust of the NHS in general and the medical professional in particular. Some Muslim Indo-Asians are concerned that health care professionals would not do as much to save their lives if they were seen as potential organ donors. They highlighted the issue of a lack respect for the body in hospitals. The majority of the participants expressed concern about the abuse of the body and its mutilation:

> *There is a lot of misunderstanding...it is well known amongst British medical staff... I have read all the newspaper and I saw so many doctors going to court... parts being removed without the consent of the parents... you do not know what is going on... this happened recently.*
>
> (Male, 62 yrs, F, C1)

> *It was reported in the BBC that doctors stole organs from patients.*
>
> (Male, 32 yrs, F, C2)

> *They are cutting a person who is dead and taking their organs out...I saw that on the television.*
>
> (Female, 28 yrs, I, C1)

There are a lot of negative things we have seen in the media like a black market in organs. From time to time these things inhibits people's willingness to participate.

(Male, 24 yrs, I, C3)

If I sign the donor card, I might not receive the right treatment. They may cut me before I died!

(Male, 22 yrs, F, C2)

It is a major operation and you did not know for how long you will survive... They are cutting a person who is dead and taking his organs out.

(Male, 33 yrs, I, C1)

I have seen a TV programme that showed some of those organs working but the rest do not work.... They have a reaction to it...Some of the patients become upset and then commit suicide.

(Female, 39 yrs, F, C1)

Doctors cannot perform miracles.... They do not save life.

(Male, 65 yrs, I, C1)

In this context, most of the participants had only a superficial interest in the field of organ donation. Therefore, they were not aware of the organ shortage of the United Kingdom in general and amongst Indo-Asians in particular. Around hundred of the 141 participants had not discussed the issue with his/her family. They felt that the subject was not that important since none of their families was suffering from organ failure. They felt that this issue is religiously sensitive and is not easy to discuss. Nearly all the participants were unwilling to discuss the issue with their family. This appeared to be because they were unsure about whether they wanted to donate or not.

We have not discussed it ...We have never come cross it.... These things only happen when your relative is ill and has need of an organ...only then do we start searching for such a thing.... It only affects you ... if any of your kin is affected...[if not] we do not really give much thought to it. (Male, 50 yrs, I, C3)

They stated that they had never been informed about this issue by any health care professionals, such as their general practitioner (GP):

I always go to the GP for my regular check-up. If it is important, why does the GP not inform us about it? I have been going to my GP for more than 30 years and he has never told me about it.

(Female, 52 yrs, F, C2)

I have been to the hospital and I did not see any posters or leaflets discussing organ donation.

(Male, 64 yrs, I, C3)

Eighty-nine of the 141 participants were unwilling to donate their own organs or those of their relatives. They believe that their religion forbids donation of organs and worry about the religious ramifications. They justified this by referring to some statements from the *Qur'an* and the tradition of Prophet Muhammad. They stressed that the issue of organ donation is never mentioned in Islam:

I used to read the Qur' an as well as Islamic books. I have never found mention that it is allowed. It seems discussion of it does not exist in Islam.

(Male, 34 yrs, I, C3)

Islam does not support that...Nothing was mentioned in the Holy Qur'an. (Male, 29 yrs, I, C1)

Allah never said anything about such a thing.

(Male, 66 yrs, F, C1)

Organ donation never existed in Islamic history.

(Female, 37 yrs, F, C1)

In spite of the participants' belief that there were no references to organ donation in Islam, they felt this issue should be referred to Muslims scholars to find out their opinion.

I am a practicing Muslim.... I do not know anything myself, but I would ask the scholars or the Imam...If they tell us it is alright; then It is alright...If they say no...that is no.

(Male, 38 yrs, I, C1)

I think this is a big issue, which should be clarified by the scholars...If it is right in Islam and if it is something we should do, we should be communicating.... We should rightly be speaking about it and they should tell us that it's something charitable we could do for humanity.

(Female, 26 yrs, F, C3)

Our local scholars are like the supervisors whom we cannot ignore.... They are sometimes of the same opinion on some issues or end up with inconsistent opinions.

(Male, 42 yrs, I, C1)

If we can get a ruling, from the scholars with evidence from the Qur'an and Hadeeth, then it is fine.

(Male, 18 yrs, F, C1)

Participants were asked whether they had asked Muslim scholars about the matter. Most of them said they had not discussed it with the scholars. One did say that he had never been asked about the subject and he suggested referring it to Muslim scholars as following:

> *I really have to enquire from the scholars and to find out if I am allowed to do that or not.... I have never really discussed this thing with any of the Islamic scholars. The best thing would be to have a decision of the scholars, people who have expertise in Islamic Shariah, to really give a judgment upon it...that will carry weight for the future if such things are allowed.... It is the only way, I suggest.*
>
> (Male, 45 yrs, I, C2)

> *The Qur'an says: if you want to find out something, which you do not know, ask the people who do. So I will not pass any judgment until I find out from the experts who have the knowledge and will give me advice.*
>
> (Female, 26 yrs, F, C3)

It is clear that the Imams` opinions have a significant effect on many people who could potentially be in favour of organ donation. Ten of the participants cancelled their organ donation card after the Imam's advice, six males and four females. One of the participants reported:

> *Actually, 30 years ago.... I had a card, which I kept with me all the time in my pocket... I want to donate my kidney after my death. That was because I was really not a practicing Muslim at that time ... But Allah give me success, then the scholars told me that you cannot donate your kidney.... Then I changed my mind and threw that card away... But now I feel that this is the way for humanity.... Personally my view is not on the religious side ... If you can save anybody's life...you should do so.*
>
> (Male, 67 yrs, F, C1)

The opinion of a senior person in the family also had an effect on participants. Typically, a female would refer the decision to her father or husband.

> *I personally have no objection but my father does, so I am not sure.... He just did not like the whole concept of organ donation... His thought is that when your time is up, your time is up.*
>
> (Female, 20 yrs, I, C3)

> *I cannot decide. I have to ask permission from my husband; also I cannot donate because I am taking care of four children.*
>
> (Female, 47 yrs, F, C2)

It was clear males felt more able to make the decision. Only two participants had an organ donor card.

> *Yes, I do hold a card...I signed it with my driving licence and I informed my family as well.*
>
> (Male, 42 yrs, I, C3)

> *Personally I think it is OK to donate, I have an organ donor card.*
>
> (Male, 27 yrs, I, C2)

However, they were divided regarding the importance of telling their families about their donation. Some of participants did not want to inform their families.

> *I did that for the sake of Allah. I do not want anyone to affect my decision.* (Male, 32 yrs, I, C3)

Nevertheless, some of the participants sympathized with the need of patients. Only twelve of the participants expressed the view that they were very likely to donate their own organs after their death. Few participants were willing to donate their organs and were really positive with the issue. Some of them said:

> *You helps other people to maintain life ...I am willing to donate.*
>
> (Female, 19 yrs, I, C3)

> *I love to help humanity.... after my death if somebody can enjoy my organs and have life ...why not...let somebody return to life after my death. I am quite willing to do it.*
>
> (Male, 38 yrs, F, C2)

However, most of the older participants did not want to donate or to allow anything to be done with their children's bodies after death. In addition, they would not allow their children to donate or sign an organ donor card.

> *I would not allow to my children to freely donate my body, not even their bodies.* (Male, 72 yrs, F, C3)

> *My children will not donate my organs to anyone, not even their own organs. They have to listen to me. I am their father and they have to do what I ask them to do it.*
>
> (Male, 68 yrs, I, C2)

Some of the participants, particularly from the older group, cited their being too old as the reason for their reluctance to become donors.

> *I am too old and my organs are useless, no one can benefit from them.* (Male, 74 yrs, F, C3)

An interesting finding was that nearly one-quarter of the participants disagreed that organ donation helps families cope with their grief.

> *Organ donation has nothing to do with people grieving.... They might come to guilt in later life.*
>
> (Female, 45 yrs, F, C2)

When they were asked about an appropriate method for organ retrieval, the participants showed that the informed consent method was the ideal way to safeguard patients and relatives rights. They considered a signed organ donor card as permission to take organs.

> *We have to be informed about any surgical procedure...relatives should sign consent.*
>
> (Female, 41 yrs, F, C3)

When I asked them with regard to giving financial incentives, most of them said they disagreed. They thought that organ donation should be done out of altruism. However, some thought that the donor's family should receive money to cover funeral expenses.

> *It is a good idea for people who cannot afford the expenses of the funeral, or who might need money after they lost their breadwinner. People are poor and any amount of money might help them.*
>
> (Male, 36 yrs, I, C2)

The groups expressed objection to presumed consent or the use of pig's organs. However, ten of the participants supported the use of other animals' organs in transplantation as an alternative to human organs.

> *Pork is not allowed for food in Islam. It is not permitted. How could you transplant its organs into a human body? It is defiling.*
>
> (Male, 20 yrs, F, C1)

I asked all of them what they would do if they were stricken by organ failure. Almost half of the participants preferred to take any treatment other rather than transplantation. Moreover, they felt that organ transplantation is not "treatment". Forty-two of the participants said that they might get an organs from abroad. They indicated that they

could find a donor from their countries of origin. However, they avoided using words like "pay for a kidney".

> *We can easily get one from India. There are many donors there willing to help.* (Male, 41 yrs, I, C2)

Questions regarding reasons behind unwillingness to donate organs brought a wide variety of answers. Although organ donation has not historically been discussed in Islamic law, there are other factors that have been identified by the participants that are considered to be obstacles to their acceptance of organ donation. They believed that these factors are significant in shaping their opinion toward this matter. These factors, each of which will be dealt with in more detail below are: the sacredness of the body, fatalism, the role of organs as "witnesses", recipient probity, and premature declaration of death.

5.4.1 Sacredness of the body

The belief that God owns the body and that God alone can make decision about its fate was frequently expressed. All of the participants believed that, in Islam, the body is sacred and that they do not have a free hand to dispose of body organs. They also believed the deceased's body must be buried as soon as possible. This is because they believed that a deceased's body is resurrected after death and interrogated about what he/she had done during life. This gives a responsibility to take care of a corpse after death as well as during life. They also believe in a judgment day, where God will ask them about their bodies and whether they took care of them not. Thus, the concept that it is desirable for a body to remain as whole after death was expressed.

Mostly, organs are taken after the person has died...In Islamic ideology basically the deceased must not be harmed and the body should be dealt with very gently and very lightly and not be moved unnecessarily. It is non-Islamic to take organs...these are the basic and fundamental reasons why Muslims do not come forward and donate their organs. (Male, 67 yrs, I, C3)

I know there is a "Hadeeth" in which the Prophet Muhammad says: treat a deceased Muslim's body as that of the living. If you hurt it, it will feel it pain. If you disturb it, you will feel the same. Going on this principle, taking any organ out of the body would cause pain to the body and that means you should not distribute body parts. Just let him in peace.

(Male, 62 yrs, F, C1)

I remember this Hadeeth from which I understand the principle of leaving the body intact as it is.

(Female, 50 yrs, I, C2)

We will not be buried fully like we are...Some parts are missing.... I would be buried without my organs.

(Female, 28 yrs, F, C1)

We think that when a person dies, he has to die with all his organs and not to be cut and to be separated. They should not mishandle the body...You should be buried properly.

(Male, 22 yrs, I, C1)

A few of the participants preferred to die at home. They do not like healthcare staff touching their bodies. They said that it is ideal that a family member should take out any lines or wires and clean the deceased body. They insisted that this person should be of the same sex as the deceased. If a person dies in a hospital, they want the death certificate signed as soon as possible to make it possible to transport the deceased body to the mosque. The body should be buried in a Muslim cemetery as quickly as possible.

My own opinion is that life is sacred and, in Islam, even the dead body is sacred.. The dead body is like the live body and should be respected... So we told to bury it straight away without delay as soon as possible. (Female, 21 yrs, F, C3)

If a person dies, take him to the grave...Do not do anything else...If it came to me at the end... keep the respect and integrity of the Muslim's body. (Male, 61 yrs, F, C1)

Also, some felt that the body would be treated disrespectfully. Words such as "mutilate" and "desecrate" were used. A few of the participants shown resentment regarding using body organs as "spare parts". Several participants felt that organ transplantation interferes with the sacredness of the human being.

The human body is not a machine. Organ transplantation is abusing the body's dignity. Our organs are not mere spare parts. They are a gift from Allah. (Male, 24 yrs, I, C2)

5.4.2 Fatalism

Several participants stated that one of the basic elements in Islam is fatalism. Several said they did believe that, if they were cured of any disease, it would only by the will of God. So, they wait to be cured by God, which is why they do not believe in organ donation as a treatment. They believe if any Muslim becomes sick, God will grant remission of his/her sins, as it is God who has put the disease in their body. They believe also that organ transplantation not only extends a patient's life but also extends his/her suffering.

> *The Qur'an teaches us that when one needs to recover from illness, one should ask Allah directly.*
>
> (Female, 29 yrs, I, C2)

> *It is not worth extending a person's life for another two years, eventually we will die...I do not want to interfere with Allah's will.*
>
> (Male, 25 yrs, F, C1)

> *When anyone dies, it is because Allah's wishes it, we are going.... but to stop us from dying and the organs they going to transplanted to somebody else...this is Allah's command and wishes.... we cannot stop it.*
>
> (Female, 39 yrs, F, C1)

> *If Allah wants someone to live longer, if a person deserves life, Allah will give him that.... If Allah wants to punish anybody, he will be sick and die.*
>
> (Male, 49 yrs, F, C1)

Nevertheless, a quarter of the participants would accept having an organ if any of their own organs failed. The majority of the participants showed little anxiety towards death. It might affect the acceptance of organ donation. They strongly believed in life after death (resurrection), which makes them concerned to in keep all their organs.

I am not worried about death... Being a Muslim you believe death has to come whenever.... we do not want to extend the life.

(Male, 19 yrs, I, C1)

Allah gives us life, and then we will die. After death there is life. Surely Allah will raise all the dead. (Female, 32 yrs, F, C3)

Death for a Muslim is not like the death of non-Muslim... We are going to a real life; after this the real life starts.

(Male, 57 yrs, I, C1)

The afterlife is better than the present life... Allah says that, so we have to make an effort for the afterlife.

(Female, 33 yrs, F, C2)

It was found that believing in life after death from the participant's point of view not only made them care less about death, but also made them more aware of their responsibility to their organs. One of the participants said:

Thus, for Muslims death is not the end of the world. It is just the start of an everlasting life. We have to prepare our bodies for that purpose, not cut it and distribute organs to others.

(Male, 39 yrs, I, C3)

5.4.3 Organ acting as "witnesses"

Muslims believe that God will call their organs to account in the Judgment Day. Some of the participants stressed that their organs would act as witnesses to their behaviour on Judgment Day. They believed that God would interrogate each organ of every individual to testify whether or not they had been used correctly and will witness to every action their owners had taken even if that testing reflected badly on the individual. They thought that God would ask the organs to report how the human had used them during his/her lifetime. As a result, they wished to keep their own body's organs.

> *When we die, our organs will speak themselves to Allah...If they are not there, then who will speak to Allah?*
>
> (Male, 57 yrs, F, C2)

> *The organs will be witness to your actions on Judgement Day.*
>
> (Male, 37 yrs, F, C1)

> *My body's organs are fundamental to my personality. I am wondering how you transfer my identity to someone else."*
>
> (Female, 21 yrs, I, C3)

5.4.4 Recipient probity

Because they believed in organs acting as witnesses, most of the participants were cautious about the individual who would be the recipient of their organs. They would donate their organs only to Muslims. Indeed, many stipulated that their organs should only go to "good" Muslim recipients, while others felt that Islam forbade organ donation to non-Muslims. They did not want to receive organs from non-Muslim as those donors may have eaten pork, drunken alcohol or smoked, all of which are not allowed in Islam. On the other hand, two of the participants showed their willingness to donate to non-

Muslim children. In summary, there was disagreement about giving or accepting organs out of their close community. This is illustrated by participant's comments such as:

We want our organs to go to our community, to Muslims only.

(Male, 24 yrs, F, C1)

We want to do something good...but when you see how some people act, I would say no. (Male, 65 yrs, F, C1)

Islam always says you should help each other but then always says Muslim only...I do not know. We first should help our Muslim brothers, and then we might look outside.

(Male, 37 yrs, I, C1)

I would rather die than have this organ.

(Female, 52 yrs, F, C1)

If it is from a Muslim person who does not drink or eat pork, yes I will accept it...because the Prophet Muhammad says if the body is nourished by non-Halal food, this part will be burn in Hell.

(Female, 44 yrs, I, C1)

I want to make sure that the person is good before I give him my organs. (Male, 20 yrs, I, C1)

We are willing to help only non-Muslim children.... but if it is for adult persons, I would not. (Female, 23 yrs, F, C1)

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5.4.5 Premature declaration of death

Some of the participants believed that racial prejudices interfered with minority patients receiving proper treatment. They insisted that doctors might take organs before the real time of death. They are less likely to believe that they will be treated fairly or that the health system treats them equitably. This was related to racial prejudice, as the participants said in various ways:

> *I feel there is a lot of prejudice. They might declare death prematurely to take organs from us and give them to whites.*
>
> (Male, 42 yrs, I, C2)

> *Who knows what the doctors are doing? How we can trust them? They are doing many experiments on patients.*
>
> (Female, 27 yrs, F, C3)

A few of participants showed anxiety about the future of their children.

> *Because of different cultures, we worry about our family and children. We used to live together, but now we have to be careful.*
>
> (Male, 38 yrs, I, C2)

It is clear that people from this community need more reassurance that health care professionals are treating all patients equitably. However, the participants did not rely on their own experience. They stated that the evaluation of the health care system required more knowledge, which only experts have. They stressed that health was the most important thing in their lives. They described it as a prerequisite for all other good and important things in life.

It is significant that one of the participants, an urologist in Ireland (38 yrs), was against organ donation. He stressed that we have to ask scholars about it. He stated that:

> *I think there is no problem to take only kidneys from living related donors, but it is not allowed from cadavers because there is controversy among the scholars.... According to our research - they should not be taking organs from cadavers.*

When I asked him what he means by "our research", he said:

> *All the Muslim doctors working in the UK like to refer to "back home" in Pakistan and all the doctors who are doing research work on organ donation and transplant surgery in the UK consult scholars from Pakistan. When we asked them about cadaveric donation, the scholars did not give permission.*

5.5 The Imam's point of view

The interviews and focus group discussions stimulated a lot of questions in my mind. One major serious question was: Are people in this community being taught that organ donation is actually allowed in Islam? What is the effect of the Imam on people's attitudes? Thus, I interviewed the Imams in the three Centres in which I had been working. These Imams had been hired from foreign countries: India and Pakistan. They do not know much about the Western communities or the way that the Indo-Asians subsisted in this country.

The three Imams were hesitant to discuss the matter of organ donation and transplantation. They stressed that there is strong disagreement between Muslims scholars. Imams pointed out that certain aspects of Islamic Law have still to be codified. They felt that the majority of scholars thought that donating any human organ whether in

life or death, has not impermissible since a man cannot dispose of his body in life or in death, nor can his inheritors or others.

The first answer to my question regard the legitimacy of organ donation in Islam was (C2):

It is totally Ha`raam (forbidden)

Their answers were mostly very similar to those of the participants. This might be because the Imams themselves were the sources of Muslims` opinions. For example, when I asked about the reason behind prohibited organ donation in Islam, their answers were different but had the same meaning as the participant's responses, for example, referring to sacredness of the body.

> *After death, non-Muslims should not touch the body. It is the family duty to wash and prepare the body. They have to bury the body as soon as possible.* (35 yrs, C1)

The Imams stressed that we do not have ownership of our bodies. Thus we cannot dispose of our organs. They stated that the body belongs to God: how can I donate a thing that I do not own? Thus, they stated that organ donation becomes lawfully invalid. One of them said:

> *A man's body is not owned by him, but by his Creator. Man is only a guardian of his body. He is commanded to do only what may benefit this trust and by no means harm it.*
>
> (42 yrs, C2)

The main reason is that our body do not belong to us. It belongs to Allah...As Muslims, we believe our body is given to us in trust.... We have no right to donate parts because, first of all, we do not have a guarantee about life after the transplant...even if you donate some organs to someone, we do not have a guarantee the person will live, or it may cause harm to yourself and to the person that you give it to. (35 yrs, C1)

They stated that the Islamic law honours the body of man, living or dead, and prohibits its abuse, disfigurement or assault of any kind whatsoever. All of them said:

The Prophet Muhammad said: breaking the bone of the dead is tantamount to breaking the bones of the living.

(39 yrs, C3)

When I asked them about the evidence from the *Qur'an*, one of them told me that:

Allah says in the Qur'an: Allah will take your body to the heaven. Therefore, we do not allow giving of any part of the body to somebody else...because we did not pay for our body...it came from Allah. (35 yrs, C1)

None of them have much knowledge of the organ donation programme in the UK. One of them told me he had never been asked about this subject before.

5.6 Conclusion

Overall, there were no significant differences between participants` answers by age, sex, and socio-demographic background as we can see from the distribution of sex, age, group, and centre among respondents. However, where participants did have more positive attitudes to transplantation they tended to be younger UK-born, who were more willing to learn more about the process of organ donation than older people. Furthermore, younger groups showed more sympathy than the older groups toward the donation of organs. In addition, older people referred most of their discussions to Islamic law and the opinion of scholars, while younger people were willing to discuss the issue in an open-minded way.

Higher levels of education have been positively correlated with support for organ donation and willingness to donate ones or relative organs. Thus, for some participants, their educational level might clarify the issue. There was virtually no difference in the desire to donate between men and women. However, women showed more unwillingness than men to take responsibility for the decision.

All focus groups and interviews expressed almost identical opinions about organ donation. Although the language and manner in which their attitudes were verbalized often differed between the different groups based on their own point of view and their level of religious knowledge gained from the Imam. Most participants did not have any personal experience of donation, which might contribute to the inflexibility of their attitudes.

Generally, although this study has many limitations, and its findings cannot be extrapolated to larger population, it has interesting implications and should be considered in future work leading to changes in public policy. British Muslim Indo-Asians were aware of the issue of organ donation for transplantation. However, there are many obstacles preventing them from donating organs.

The participants were currently largely unwilling to donate their organs or those of family members. Having a more accurate knowledge about the process of organ donation might help them be more willing to accept an organ donation.

GPs and healthcare staff should be encouraged to discuss organ donation with the public in the general, and ethnic minorities in particular. Since the findings from this research study indicated a significant relationship between religious belief and willingness to donate, more information is needed to explain the Islamic view. Religious barriers to organ donation appear to be the main reasons.

As mentioned in chapter 1 in regard to the role of the health care professionals in organ donation as a provider of the services, the next chapter investigates their opinion of the current situation and their views for the future.

Chapter 6

The role of the Health Care Professional in the UK transplant programme

6.1 Introduction

In Chapter 1, it was indicated that several approaches have been adopted to solve the problem of organ shortage. I decided that it would be useful to investigate the opinions of health care professionals who are interested in this issue to address the effectiveness of alternative solutions to the shortage of organ donation in practice. Thus, in this chapter, I shall present the findings of interviews carried out on a sample that represents three categories of professionals in the field of organ donation and transplantation.

To begin with, ten health care professionals who work in West London Hospitals and have experience with Indo-Asian patients were interviewed. These hospitals included the Hammersmith Hospital (HH), Charing Cross Hospital (CCH), St Mary's Hospital (SMH), and the Royal Free Hospital (RFH). These individual were physicians and surgeons actively involved in renal transplant programmes.

As previously mentioned in Chapter 3, the nature of the interviews used was unstructured. Questions were open-ended, but included topics related to the issue of organ shortage in the Indo-Asians population in particular. Participants were also questioned about suggestions to improve the rate of organ donation, the main factors that prevent people from donating their organs and their opinion of the transplant service in the UK. In order to maintain confidentiality, names will not be used, just single letters to identify different individuals. The interviews are quoted at some length because of their central relevance to the research study. The term 'participants' will be used instead of 'health care professionals'.

Next, I interviewed four researchers who have researched the problem of Indo-Asian organ shortage: researcher one is a transplant surgeon, researcher two is a principal lecturer in Health Services research and a member, UK Transplant's Board, researcher three is a GP and primary care researcher, and researcher four is a member of the Muslim Law Council. In the main, questions inquired about their interest in the subject and their perspective on how to solve the problem.

In the third and final category, I tried to try and understand the position taken by the "Establishment's" organ transplant programme in the UK. Interviews were conducted with Mrs Jane Griffiths, the manager of the North Thames Region Transplant Co-ordinators, Mr Chris Rudge, UK Transplant Medical Director and Dr Peter Doyle, the Senior Medical Officer of the Department of Health. During the interviews, they were asked about their role and their thoughts about the future, I ended discussing the findings with them.

At the end of this chapter, the current legislations affecting organ donation in the UK: the Human Tissue Act, 1961, and the Human Organ Transplant Act, 1989 are discussed.

6.2 West London transplant professionals

In this section, the opinions of West London professionals and the options for improving the supply of Indo-Asian donors are discussed.

6.2.1 The organ donor situation at present

Each participant's interview began with a discussion of the organ shortage in the UK in general and in the Muslim Indo-Asian population in particular. In general, all of the participants emphasised that the situation was critical and needed immediate intervention:

> *We have a large Asian community and there are no donors from these communities. For Asians in particularly, there are severe organ shortages.* (L)

> *Indo-Asians more likely to get end stage renal failure, so you always need large numbers of donors who are Asians, but Asians do not donate as frequently as others.* (N)

The participants had many different views about the reasons behind the shortage of Indo-Asian donors. The majority felt the Muslim Indo-Asian community itself was the main cause of the shortage. One of the participants was uncertain about the reason. Although he was uncertain about the reason, he stressed that culture and religion played an important role in shaping the decision regarding donation among Muslim Indo-Asians in that they would only give their kidneys to people from the same community as themselves:

> *It could be religious; it could be cultural. I have seen a family who are happy to donate to their father but he would not accept it. They have issues with burying bodies that are missing organs, and some people even say that they do not want their organs going to white people.* (N)

On the other hand, some participants stressed that the issue is related to culture rather than religion. Also, one of the participants argued that in some Muslin Indo-Asian families, decision-making is dominated by men:

> *I am sure that the main problem is cultural and it is more of a perception than, after that, there are religious problems. I am sure they have a complicated family structure, and I do not understand the family dynamics. I think the issues are more cultural because the Muslims issued a fatwa at some point saying that transplants do not go against Muslim principles.* (C)

Another participant felt that the decline in the Indo-Asian donation rate was because of the media. He stressed that media has played a role in misleading the public:

> *Overall, organ donation in the country has been going down because of bad publicity. People do not want to give their organs because they are scared that they might be used for inappropriate patients or their organs may be sold etc...* (N)

The majority believed that the main reason for low donation lay in the Indo-Asian community. In addition, a few participants blamed health care professionals. One participant criticised the role of health care professionals who are work in Intensive Therapy Units (ITUs). She believed that they could do more to identify potential donors. She strongly felt that more education was needed:

> *I think there is a major shortage. I think there is a lack of awareness and a lack of willingness amongst staff to ask relatives who could be potential donors. I think that the ITU staff do not actually know how to approach families, compared to somewhere like Spain where every unit is aware. Therefore we need to educate our staff better.* (L)

6.2.2 Alternative solutions

The participants suggested several alternative solutions to encourage organ donation from the Muslim Indo-Asian community. One participant suggested that health care professionals should allow the Muslim Indo-Asian community to become more involved and build a partnership with them. He suggested that the donation rate will increase if health care professionals open a dialogue with Muslim leaders to explain to them the issue of the severe organ shortage among the members of their community:

> *For a long time I have thought that the solution involves establishing a relationship with the community, and not separating that from the issue of transplantation and donation. The only way we get a community to change is by making them feel that they are part of, for example, the renal replacement programme at the hospital. They need to feel that they are part of the process. We need to establish a dialogue with the Muslim leaders, we need to show the people how we can help them, setup Muslim patient groups and we need to find out how they want to do things. Once this happens, I think that the numbers of donors may even increase.* (F)

Several participants noted the importance of this relationship between local community members and the Muslim Indo-Asian population. Although there is an Islamic *fatwa* regarding the issue of organ donation for transplantation, most of the participants stressed that it is important to send a message through a member of the community, as different communities abide by different rulings. One participant recalled:

> *I was once invited to participate in a television debate about transplantation and I was on a panel with two Muslim leaders. I was asked whether or not it was acceptable for Muslims to donate organs. I said that as far as I knew there was a fatwa that allowed Muslims to do so. Immediately the man sitting next to me, who was very religious, said that my statement was only in regards to Pakistanis and had nothing to do with the rest of the Muslim world. Although I had documents with me in both Arabic and Urdu stating my case, the man still maintained that it was only for Pakistanis.* (N)

In addition to the importance of local *fatwa*, several participants stressed that the donation message should be sensitive to the local community. All of them were agreed that any future campaign to the Muslim Indo-Asian community must contain a directed message addressed by local members of the same community:

> *Religious beliefs are an important issue to address. We have to be culturally sensitive and know what issues are important to individuals considering donation. We need to know their anxieties and to speak to them in a language and use terms that they can understand. Therefore, we need to involve people from their communities in these discussions, people who are aware cultural sensitivities.* (A)

One participant emphasised the role of the Imam in the Muslim Indo-Asian community. However, he thought that most of the Imams were not qualified to discuss health issues with the community. In addition, he argued that Muslim Indo-Asians needed educational courses on Islamic health issues, especially regarding the body after death:

> *Religion is one of the driving forces within the community. The Imams play an important role within the community but many are not that knowledgeable when it comes to medicine and Islam, as many are not really scholars. Regarding Muslims and burials, many think that you have to be buried with all your organs, and even if their kidneys were full of cancer, they still would not want them thrown in the bin! They do not see that no religion would want your body to be full of cancer.* (M)

Finally when I asked one participant whether she would involve herself in activities for the Muslim communities, she spoke of her own fears and concerns. She was mainly worried about how religious leaders would take to having a non-Muslim woman talk to them about these issues. She did not know whether a woman would be welcomed or even how appropriate it would be. She was worried that they would lose many potential donors because they did not like having a woman telling them what to do. She also believed that all future campaigns had to be specific for each religion:

> *I think that we have to understand religion and culture, and campaigns have to be culturally specific. There is no point having a blanket message for all Asians.* (L)

Another participant felt that he could not participate in any campaign because he was from different religious background as he indicated:

> *I am actually a Christian and I certainly would not know what to tell different communities.* (N)

6.2.3 Financial incentives

Interestingly, some participants encouraged the idea of giving donors financial incentives. From their experience, they found that many kidney failure patients went abroad to buy a kidney, which in some cases was found to be poorly compatible or infected. They stressed that this situation costs the NHS more money and wastes their time as they end up treating a new problem. They felt that NHS should allow financial incentives to enhance organ donation. They insisted that many health care professionals had the same view:

> *I personally think that it should be allowed. I believe that giving out a reward is a good idea. This is because whether we like it or not, people are going to buy organs, although it is better if this does not happen and donation takes place in a more organised way, like in Iran or India. In addition, if people are not allowed to buy kidneys, then they will do it in secret, which means that people may become infected with viruses such as hepatitis or HIV. This is what I have seen happen. A lot of Asians go to India to have transplants done and come back with many problems which we have to try to fix.* (N)

I have been talking about doing transplants commercially now for more than five years, but never openly because of all the propaganda and counter-propaganda and also because people think that you are horrible. With such a severe shortage of organs, in these cases, the donor becomes a most important person. Since commercial donation is illegal in this country, there is no regulation and inspection, and so we end up receiving rubbish kidneys. I have one patient with TB and another with a sarcoma acquired from the kidney they bought. If you regulated commercial donation and there was an independent body like ULTRA in this country, then I think that giving people financial incentives to donate organs would become acceptable. I did not always think like this until I thought about what was going on in the rest of the world. In Brazil for example, there is a story of some people walking along a beach and finding the bodies of two children with their organs removed. Therefore by not regulating commercial donation, it may lead to misery. Why should organs be obtained in the black market when they can be inspected properly and the donor and recipient can receive the right medical care in a good centre? (M)

On the other hand, one of the participants felt that incentives should only be allowed to cover expenses.

I think that there is a risk of corruption by offering incentives. I do not think we should do that. However, I do think we should pay expenses. (A)

6.2.4 Conditional donation

When discussing the attitudes of Muslim Indo-Asians, some professionals raised the issue of conditional donation and this point was addressed during subsequent interviews with this group. All of them were against it without hesitation. They preferred to avoid any discussion about this, as they felt that it was highly contentious. They believed that distinguishing between people in the same community might lead to conflict:

> *No not at all, I just think that if you are going to give a kidney, then give a kidney. I think the idea that you going to give a kidney and you get to select who you are going to give to is not right.* (E)

> *I personally feel uncomfortable with it. I think we have to be imaginative in the way we interpret the rules. There is a problem, but we would not like a conditional donation in the opposite direction: Caucasians saying they will only give kidneys to other Caucasians. Somehow, the use of religious criteria rather than ethnic criteria appears more acceptable. I think we should be looking at more creative ways to responding to a popular anxiety.* (A)

6.2.5 The UK donation system

Some people in the British medical community talk about applying an "opting-out" donation system as will be discussed later in this Chapter. This issue split participants into two groups. Those who advocate an "opting-out" system suggest it might work as a motivator to the public to donate their organs, as can be seen from the following quotations:

> *I agree with opting-out because I think that it makes people think about the situation. However, whether you opt-in or opt-out, you will still have to ask the relative for permission to take an organ.*
>
> (F)

> *To have more donors obviously you have to have a change of the system, where everyone becomes automatically a donor. I believe we can work more on teaching people to accept the fact that they have to decide for themselves if they want to donate or not.*
>
> (N)

Others thought that staying with the current system retains peoples` freedom to make the decision:

> *I think even if we had opting-out system, most surgeons would not perform an operation unless they had permission of the relatives.*
>
> (S)

> *I think it is more democratic, rather than the Spanish or French system, where the organs belong to the government and they can do anything with them. It is too aggressive I believe. I would prefer to stay with the same system and change the mentality of patients and families.* (E)

6.3 Researchers interested in the attitudes of Indo-Asians

As mentioned in chapter two, there are a few studies conducted in the UK whose authors were interested in the attitudes of the Indo-Asian community towards organ donation for transplantation. Interviews conducted with some of these authors generated the following findings.

6.3.1 Researcher 1 (R1)

The interview began by questioning the researcher about his interest in the subject, to which he said that he and his colleagues did not have any interest until they faced the unpredictable number of Indo-Asian patients on dialysis since they did not have enough donors. Therefore, with the demand being well above the number of organs available, they decided to investigate the situation in order to find a solution. Also at the same time, the community was labelling them as being "racially discriminatory", as he indicated:

> *There was a problem for them and a problem for the Unit. The problem for them was getting kidneys, and the problem for us was a very rapidly expanding dialysis population, so they were over represented but at the same time, not being transplanted. Therefore, in the population of the West Midlands, Indo-Asians represented something in order of seventy per cent, but in transplantation, only ten per cent of the transplant population were Asians. The reality was there is an obvious shortfall between the demand that was there and the supply. So I suppose I was starting to get anxious because our Asian patients were getting obviously and rightly concern about this and I was starting to get questions like 'Why is it that we get the dialysis and we see all the white guys getting kidneys?*
>
> *ALKHAWARI (2003)*152

Thus, they started campaigns to increase cadaver donation. Unfortunately, they discovered that none of these campaigns was successful and resources were wasted as he revealed in the following conversation:

> *Overall, cadaver donations had fallen. There have been campaigns aimed specifically at certain ethnic groups, and considerable resources have been expended for relatively few extra kidneys. So on this basis campaigning was not the right thing to do.*

Therefore, he and his colleagues performed a survey to investigate the attitudes of young Asians in their area, by asking them about their opinion about organ donation for transplantation. They found that although most of them were interested in donating his/her organs, they felt that their parents and other seniors in their families would stop them.

Interestingly, they found that, while Hindus and Sikhs were very clear as to whether they could donate or receive organs, young Muslims particularly were very much more "confused". Even when these young Muslims had the transplant *fatwa* discussed with them, they were split in their view as to whither their religion would allow them to be donors or recipients. When asked what he meant by "confused", he said:

> *We asked very specific questions to the young Asians: Does your religion allow you to be an organ donor? Does your religion allow you to be organ recipient?' If you ask these questions to Sikh or Hindus, you get something like ninety per cent of people saying, 'Yes, it does'. However, when you ask Muslims, the response was forty-seven per cent saying, 'Yes it does', and fifty-three per cent saying, 'No, my religion does not allow me to be a donor or recipient'.*

As they began to understand the problem, the team directed their efforts towards the Muslim Indo-Asian community, rather than Hindus and Sikhs. However, as they found from their study, extended families are important in the Muslim community They came to the conclusion that the best way forward was to encourage living donation. Thus, they funded a living related programme and employed the first local live donor co-ordinator, specifically working in the Muslim Indo-Asian community. However, after extensive work, the results were disappointing, as he reported:

> *We found that we could not wait for generational changes to occur, and that we had to do something to start things straight away. Live donor transplantation is the way you can respond immediately. We put a proposal together...We got funding for the country's first Asian live donor collaboration. The plan was to go to every transplant recipient on the waiting list, and interview patients with their families. In addition, we tend to educate them about the problems Asian patients face regarding kidneys, and then bring up the concept of live donation to see if we could encourage those families to donate. We had the view that Asian families tended to be bigger, more centralised, and "into self help", and we were expecting donors to be emerge very quickly; we were wrong! We got very disappointed, because in the first year of that campaign I think we did one transplant only! And that one would have happened anyway. Unfortunately, in subsequent years, the numbers were still very small, and in the mean time we were not really increasing the number of cadaver donations.*

He argued that the traditional view in the Muslim Indo-Asian community is that they are "unsympathetic to donation" due to the religious concept of sacredness of the body after death. Although they are not willing to donate their organs after death, he said, most of them are willing to buy a kidney from India or Pakistan. He was confused regarding

what the problem was and why the Islamic *fatwa* from the Shariah Council was not accepted by this community.

> *I do not know what the problem is; I think that is a question I would have to put back to the Muslims. I do not know enough about it. I have been told about the fatwa produced in this country that was predominantly described to me by Arab Muslims, whose views do not necessarily apply to all Muslims! Our local Muslim community is predominantly Bangladeshi and Pakistani, but I do not know whether that is true or not? It is just that I have been given that explanation by a number of Muslims.*

However, he stressed that they continued to encourage the Muslim Indo-Asian community to co-operate with health care professionals to find a solution. He did suggest that Caucasian health care professionals were not capable of dealing with this matter because they came from a different background. Accordingly, he insisted that it fell to the Indo-Asian community itself to take action.

> *I think the messages cannot come from me, and that is the first thing. I think we have to empower the community, by getting a message to the community that says: You have got the problem. We have no problem in performing a transplant for everyone. We are very happy to transplant people whether you come from Birmingham or anywhere else. It does not matter to us, we transplant everybody, but it has to be recognised that within the community, there is an issue, there is a problem, and we can help by giving information to that community. But at the end of the day, the community has to move forward itself.*

However, although he thought that this message would encourage people to donate their organs, he realised that the way to deliver it would be different for each community and had to be delivered by a key, local person.

> *First of all, I do not think that this message should be different for different people. I think that you firstly need to identify each group. The message is that transplantation is a good thing to do. However the route of delivery has to be more direct. If the message is that there is a lot of renal failure in your population and you need to do something about this, it should be said in Urdu or Arabic, and taken into the community by the members of the community.*

When asked, as a health care processional working in the field of transplantation, about his own ideas for increasing the rate of organ donation, he argued that the most important thing is to have a transplant co-ordinator as in the Spanish model. However, he was concerned for the future of the cadaver programme and other alternative solutions such as xenotransplantion and non-heart beating donors. He thought that the future is living donation:

> *I think that the Spanish model is very good and has certain benefits. I think that if we have a transplant coordinator everywhere talking to people, then I think we may get more kidneys. But I think the outlook for cadaver donation is actually shrinking. It will always be there, but I do not think it is something to rely on. I think living related donation has got a big future, and I do not see many alternatives at the moment. I think xenograft transplantation is still many, many years away. Non-heart beating donation again comes down to the sort of the problems with regard to taking organs out the bodies very soon after death, consent and whether you are actually assaulting the*

> *body. It becomes other people's business, it is also hugely resource dependent, and you need a lot of people on call all the time, able to respond anytime.*

However, he criticised the current law on organ donation and stressed his desire to see it changed it in order to give a donor control over the decision rather than his/her relative. In addition, he would encourage recipients to provide financial incentives to the donor:

> *I think something could be gained in this country by changing the law regarding the removal of body parts after death. At the moment, although they say you can leave all your money to the dog's home and your relatives cannot challenge that, if in your will you say that you wish your organs to be used for transplantation after death, this has no legal standing. Your relatives can always override your wishes, so you have no rights after your death over your own body parts. In this country the debate is still raging. I think to myself, who owns the body if you do not own your body after death? The other area that seems more controversial is the concept that, if we are going to increase the number of live donors, how we will do it. There are a number of places in world that say you should pay people in the form of compensation, in other words you are paying for the loss of their organ.*

Finally, he showed a strong resistance to conditional donation.

6.3.2 Researcher 2 (R2)

The interview with researcher two was totally different to any other. Based on his research, he had reached the conclusion that there might well be "inequalities" in the treatment of Indo-Asians in the health system. He said that when they started their work ten years ago, nobody was interested. However, he argued that cost makes everyone interested. Nonetheless, he felt that the Government has not taken the issue of organ shortage among the Indo-Asian community "seriously". He criticised transplant professionals for failing to register the importance of ethnicity. In addition, he argued that most Indo-Asians are diagnosed at a late stage in the natural history of kidney disease.

> *Throughout our research, we have discovered that there are a lot of inequalities within the health system. At the most basic level, until a few years ago people would not even collect data on the ethnicity of patients waiting for transplantation or on dialysis. This was a bit strange given that most areas of the health service were beginning to collect that kind of data. When we started to look deeper, we found that a lot of Transplant Units and Dialysis Units had a disproportionate representation from South Asian communities. Then over the last few years, because of the Government and UK Transplant, Transplant Units are beginning to collect ethnicity data. This data has actually shown what everybody feared, which is that we have a massive disproportional representation of South Asian patients. The number of renal failure patients will grow more quickly and sooner, which means the pressure on Dialysis Units and Transplantation will be massive, which is where we started. The Government is interested in our work essentially because now they realise that dialysis beds are getting full and the problem is going to get worse and worse. Since it costs a lot of money,*
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suddenly, everybody is interested. When we started our work ten years ago, nobody was really interested because it was not really an economic problem, whereas it is now as it is beginning to attack the Government financially, and everybody is interested in this problem.

He stressed that the issue of organ shortage in the Indo-Asian community is spread throughout the UK. However, he felt that there is delay in discovering new cases in this community.

> *I think it is a national issue. Nowhere in the country has anybody been able to deal with it, anywhere you have South Asians, you see massive inequality. It is everywhere you go from the north of the country to the south; you see high rates of diabetes among the South Asian population. For whatever reason, they seem to be diagnosed later with renal disease which means they are more difficult to manage.*

He asserted that the shortage of organ donation from the Indo-Asians community is not because they do not want to donate, but because they are not aware of the problem. He stressed that there is an underestimate of the community's need; he suggested that any campaign should take in account the level of education, life style, and implement a long-term plan to approach the whole community:

> *One of the key issues is that it would be ideal if a lots of South Asian individuals came forward because then that would obviously help with tissue type matching. From the research we have done, we have seen that it is not the people and the fact that they do not want to donate, but the fact that everybody believes organ donation is specifically linked to death. Even though it is a subject that we are all talking about openly, we seem to have an*

expectation in this country that if you just give people information they suddenly do something with it and make a decision. You cannot expect that of a community, especially when we know that they are not as well educated as everybody else. They are poor and they have lees awareness about these issues. The UK population has known for fifty years that smoking causes cancer but people still smoke; why is it that the Health Service providers expect Asians suddenly in the few years since they were told about organ shortage to go out and do immediately?!

In response to the question about the proper way to approach those people, he replied:

In our research, we found that people want to be sat down with others and allowed to digest the information, ask questions and think about it with friends and colleagues. They also want time to think about issues around religion, and have the opportunity to have a dialogue within the community. Then they are far more likely to take part in organ donation. But importantly, the way organ donation is being approach in this country is very short term: let's do a campaign in different languages, videos, leaflets and posters will not work, without actually going into the community. Campaigns are only likely to work on the second and third generations of South Asians who have been born in this country. This makes them more likely to be able to access literature. However, the first and second generations are not going to be able to understand this literature and you need to target them because they ultimately need to give consent. This is why actually investing in those community and going in there, training local people to take these messages forward, start these debates getting professionals to go in there, not waiting for patients to go to the hospital, not waiting for the community to

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invite you in to help them, is more beneficial. Unfortunately, in Britain we seem to have a very short term to approach to these problems. If we do not make more of an effort, we will have a big crisis in the UK over the next ten years, as we will not be able to reach our targets.

He was asked why his research minimised the role of religion in the decision to donate organs. Although he believed that religion does not prevent people from donating their organs, he felt that most people would like to know what their religion says about the issue of organ donation. He thought that people only needed to be reassured:

When we look to the potential role of religion, it is interesting to see that religion does not stop anybody donating. However, people want to know what their religion says, which is very understandable. They usually say, 'I would like to make a decision about this, but unless I know what my religion says, I am not sure if I am able to make a decision'. This was a very important message for our research. It made us see that you need to give people as much information as you can and you cannot expect them to find it out for themselves, because why should they? They are not able to access this information, and unless you can show them, there could be a problem. What we found however, was when you actually explained to people and demonstrated that there are big problems around kidney disease and transplantation, they are actually very surprised, and were desperate to help, as they thought that the problems were terrible.

However, he took a different position when he started to talk about Muslims:

> *The biggest request for information on religion was from the, Pakistani and Bangladeshi Muslim communities. They both wanted to know what their religion's perspectives were. On the other hand, we found that Hindus and Sikhs were happy to find it out for themselves: "I think my religion would support this", and they would not bother listening to what somebody said. However, with the Muslim community, they actually want to hear the Muslim position first, which again is understandable. We know this because when we looked at most health and lifestyle issue in UK, we found Muslim communities were far more attached to their religion. So, if you like, their religion actually influences the way they live their lives to a larger extent. This is where the Sikh and Hindu, and the Asian Christian communities differ, in that although they are, if you like, religious, the ways they live their lives are not influenced to such extent.*

He was then asked him about his view of the best way to encourage Muslim Indo-Asians to donate their organs. In his response, he stressed the use of local people who are experts in the community, and training them to raise the awareness among the community, together with giving people time to think about the issue:

> *What I think we need around the country, is to work with the community, where they live, and identify, who there currently is for them in their community to talk to, when they want to get information. They need to know whom to listen to, because the big mistakes being made in this country are when we try to set up a new structure. We need an up-to-date network, and the way to do it is to train up community workers, and get them to facilitate these groups.*

Finally, when asked about the proper donation system, he thought that the Spanish model works by training specialists in all hospitals, which we need to adopt in the UK. In addition, he disagreed with conditional donation and favoured keeping the "opting-in" system.

6.3.3 Researcher 3 (R3)

He argued that Muslim opinion is divided. He stressed that the *fatwa* from the Muslim Law Council will have a widespread effect among the next generation of British Muslims.

When I asked him why he investigates the opinion of a group of Muslims, he said that he felt that the Muslim community is a large ethnic minority group in the UK, which needs to be considered. However, he emphasised the role of religion in the Muslim's life to a much greater degree than had researcher two.

> *Muslims are now Britain's largest religious minority community, and therefore warrant study in their own right. Furthermore, there is an increasing body of evidence suggesting that religious factors are important in the decision to donate organs or not.*

Responding to a question about the shortage of organ donation from Muslims Indo-Asians, he felt that this shortage flowed from that fact that the Indo-Asian community has a high incidence of diabetes and hypertension. But he also believed that there are religious factors preventing people for donating their organs:

> *Yes, there is a real shortage amongst Indo-Asian Muslims. I think the main factors are: excessive demand - particularly for renal transplants because of the disproportionately higher prevalence of diabetes and hypertension - and perceived or actual religious barriers limiting the willingness of people from these populations to donate organs.*

He stressed that educational campaigns, including the production of material aware of religion position, are important to encourage Muslim Indo-Asians to donate.

> *Education must be the key. I think this will be easier amongst second- and third-generation Muslims. An education trial is needed.*

6.3.4 Researcher 4 (R4)

I wanted speak to someone from the UK Muslim Law Council which has issued the only national *fatwa* in the UK. Thus, researcher 4, who has participated greatly in encouraging organ donation among Muslims in general, was interviewed.

He described the main role of the Muslim College being to train Imams in how to adapt themselves to live in Western culture and about other religions, as well as speaking to Muslims who will be westernised in all aspects except religion and being able to address the wider community. He also explained what Islam is all about:

> *In 1998 this college was opened for every Muslim, a fact that is very important. We actually present to them the deep and broad study of Islam in all schools. We taught Imams from different schools to understand other religion, which is very important. We give them a very intensive course in Western civilisation and Western culture and particularly Western philosophy. We train them for the media, research, and the student has to get a degree. After the course, they have to write a dissertation and it has to be based on a topical issue.*

In addition, he described that they have the Law Council alongside the College, which consists of fifteen members, twelve different Imams from different schools of law, and three practising lawyers. This means that they have experts as well as those who are

from leading mosques and others groups, to discuss and resolve the issues of the Muslim community in the UK. He stated that they release *fatwas* by holding special meetings, to which they invite other leaders of the community to join the original fifteen, and discuss important issues such as organ transplantation.

When asked about the *fatwa* on organ donation, he replied that the Queen Elizabeth Hospital in Birmingham raised the issue in 1994. They wrote to him to say they had around 1300 Asians in need of a kidney transplant but very few kidneys were forthcoming from the Asian community due to a religious barrier. He and his College went to Birmingham and were shown the procedure used to take organs from a cadaver, had specialists discussed with them the concept of death and the possibility of removing a kidney from a living donor. Later on, they studied this issue carefully and explained to colleagues the need for the *fatwa*.

He argued that the *fatwa* is based on the precedent, in the Middle Ages, when scholars issued a *fatwa* so allowing the donation of bone from a dead person. In addition, he described that the second principle of saving lives is one of the five aims of the *Shariah*, whereby anything that will protect life is acceptable. Regarding organ donation from living people, particularly the kidney, he said that these had to be a donation and not to be paid for. This does not however mean that the people who receive the donation cannot buy the donor a gift but this should not be a condition. I then asked about sacredness of the body is Islam:

> *Most scholars argue that the body is owned by God and nobody can tamper with it. However, this is rubbish and nonsense. You owns your body and you have the right to deal with it. Yes, God own a soul. He owns everything. However, God also instructed me to save other people's lives. This is one of the aims of Shariah, and therefore, if my body is needed to save other lives, I will use it for that purpose. You have to save life regardless of whoever it is, without any discrimination. After all, we accept blood from every*

source. A blood transfusion is accepted because it has become common and people have become familiar with it.

We discussed why most Indo-Asian Muslims do not accept this *fatwa*. He strongly criticised them by saying:

The imams coming from Pakistan, India and Bangladesh are extremely inflexible and they are connected with political movements. Many of them do not speak Arabic and, if they speak it, they speak it badly. If they read the Qur'an, they do not understand its meaning. It is very difficult to argue with them. Nevertheless, if they attend a course, they might change and, once this happens, then they may not become passive elements against the community. I have been campaigning that we should stop importing Imams into our country, as well as campaigning that Imams who come here would have to take courses with us.

He suggested that Health Authorities should invite a large number of Imams to courses, because he believes that most of these Imams are trying to isolate the Muslim community from the rest of society.

In my view, the only thing we can do is educate. We need an extensive programme, the young need to have their religion, but their religion cannot survive if it stands against medical advances or technical developments. We have to absorb these and take them on board. If we do not do that, we will be unfit for Western life and that is the problem. Our mission in this College is to prove that Islam is capable of absorbing Western life and the new technology.

To summarise the interviews with these four researchers, they all highlighted the issue of organ shortage in the Indo-Asian community. They are trying to find a solution in the context of their own experience with the community. In addition, they feel that the issue is more critical within the Muslim Indo-Asian community. However, it appears that they are working independently and locally rather than nationally, whereas their efforts should be concentrated under one umbrella such as UK Transplant. Further national research is needed within this community.

6.4 The Transplantation "Establishment"

In this section, an analysis is made of the interviews with professionals who are in a position to influence a public policy directly.

6.4.1 The North Thames Region Transplant Co-ordinators

Mrs Jane Griffiths was, at the time of our interview, the manager of the North Thames Region Transplant Co-ordinators. She felt the problem was not with the public, but with health care professionals who are losing many potential donors. She believed that one of the main difficulties they had was trying to get the message across to health care professionals that they should offer organ donation to whole families. They should not be making a decision as to whether the family would agree to donation, based on the ethnicity, colour or religion of that family:

> *You cannot look at the family and say that this family will definitely say yes or say no. We have in fact found that in many cases, there are groups of people who are less likely to be asked to donate organs because of the pre-conceived ideas of those asking them.*

She argued that many potential donors are missed because staff make assumptions about them. In practice, she found that ITU staff avoided asking certain people, such as Muslims or Jews.

> *Some of the ITU directors would say to us that Muslims and Jews do not donate. So, what we say to them is that they cannot possibly look at someone and know what their inner beliefs are. People have individual feelings, and we should be offering donation to everyone. Basically, I would say that someone could be a white Christian who may say no to organ donation, while another can be a Muslim, who will say yes. We have seen this in practice. I therefore think that the main problem we have is dispelling this myth that you can decide who will say yes or no, and we are trying very hard to say you have to ask everybody.*

It was noticeable that she does not believe that there is a problem with Muslim Indo-Asian community. She concluded that there has not been enough research to say that Muslim patients on ITU do agree to donation. She criticised the data in Birmingham as being inaccurate and felt that the high refusal rate was particular to the local population. Without further research, she would found it is difficult to comment further.
In response to the question of what is behind a possibly increased refusal rate within the Indo-Asian community, she stated that:

> *We have more people waiting for a transplant in North Thames than anywhere else in the UK. When we look why that is, it is partly because the makeup of our population is high in ethnic minorities. In London, thirty-two per cent of the patients waiting for a kidney transplant are from ethnic minorities. Yes, we have an issue in London of a larger number of people from those communities waiting compare to national figure, but I would argue strongly that this does not then mean that these people do not donate. Asian people are three times more likely to have*

renal failure, and three times more likely to be in ITU brain stem dead. These two observations are unrelated, they are not the same.

When I asked her about conditional donation, she was very negative and suggested updating the organ donation law:

No, I do not agree with conditional donation. I would only support it if someone died and a member of his/her family had renal failure. I think it is extremely harsh, if you are not able to make a donation during your lifetime, why should not you able to do so after you died? Regarding the law, as you know, we have not reviewed the laws on organ donation in this country for forty years and I do not think the current law can deal with the complexity of the world in which we live now. Indeed, that is acknowledged by the Department of Health.

6.4.2 UK Transplant

Mr Chris Rudge is the Medical Director of UK Transplant and works as a Consultant Kidney Transplant Surgeon at the Royal London Hospital. When asked about the role of UK Transplant in organ donation, he preferred to discuss their activities in general since it was formed. He described that in the UK, until the year 2000, there was no single organisation that had any responsibility to improve organ donation. Organ donation was under the auspices the local transplants units and the local transplant co-ordinators. The way in which local transplant units worked and the way the local transplant co-ordinators were employed were independent of one another. In July 2000, all organisation was centralised in Bristol under the UKTSSA (United Kingdom Transplant Support Service Authority) which was later renamed UK Transplant (UKT). UKT was established as a special health authority within the NHS and was directly accountable to health ministers in Scotland, Northern Ireland and Wales through the Department of Health (DoH) in England.

In response to a question regarding the shortage of organ donors, he pointed out that, for the first time since the year 2000, the organisation has been given the responsibility of improving organ donation rates and transplant rates. He explained that they were established after a ten-year decline in the number of organs transplanted in the UK had been experienced. Therefore, they have been given extra duties, which include increasing the number of organ donations, providing a national framework for donor co-ordinators and in, April 2003, UK Transplant took on the additional role of providing publicity material. When asked about their plan to encourage organ donation, he agreed with Jane Griffiths in regard to the role of ITU staff. He said:

> *There are three specific projects that we are supervising, and which we have been given by the DoH. The first project is called the Donor Liaison Nursing Programme. It aims to get ITU nurses to refer all potential donors. The intention is to make sure that everybody within an ITU understands organ donation, understands the criteria for organ donation, understands the process, and is supported if they have major anxiety or major problem of who should approach the next of kin. The second project is to encourage non-heart beating donors. The third project is to encourage living donation by funding live donor co-ordinators.*

He was asked about campaign material and posters that was directed toward Muslim Indo-Asian community. He expressed anxiety that this might not work within the Muslim Indo-Asian community. He pointed out that they were working specifically with a group in Bradford in terms of what material would the most useful to help Muslim communities improve understanding. Again, he agreed with Jane Griffiths about insufficiency of data such as the numbers of Muslims on the Organ Donation Register:

I think there is much information still needed. We have one or two studies, not good studies and with small numbers. But none of these studies suggests that fewer Muslims Indo-Asian patients are being treated in ITUs. There is a gap in the data about the number of them admitted to hospitals. I have to say it is my understanding is that, until recently, the Muslim Indo-Asians have not being registered on the Organ Donor Register in any significant numbers.

He believed that UK Transplant is more about working at the national level looking to promote national understanding and that the educational activities will become the responsibility of local people working under the umbrella of UK Transplant.

At this stage, the approach to any family would come either from an ITU or from the local organ coordinator. However, UK Transplant is looking at the potential benefits of having somebody available who understands and can represent the Islamic understanding.

In response to the question about conditional donation, he was somewhat reserved and said that it was unacceptable and that donation should be altruistic and unconditional. Although, he felt that changing the law on donation is the responsibility of DoH, he believed that "opting-in" or "opting- out" is "irrelevant". Organ donation legislation needs to be reviewed.

I think we could actually change not the legislation but the interpretation of it, if you look carefully at the 1961 Act there was built into that almost a presumption in favour of donation. We need to change the access people have to donation instead of the law, so that donating organs becomes more of a norm.

He agreed that none of the campaigns has been very successful. It seems that the role of UK Transplant is to apply the strategies of DoH to promote organ donation for transplantation through local organ donor co-ordinators and to implement a suitable communication strategy that will suit each community separately.

6.4.3 Department of Health

I felt that I should address these questions to a higher health authority such as the Department of Health, to find out what is planned to solve the problem of organ shortage among the Muslim Indo-Asians community. Consequently, an interview was conducted with Dr Peter Doyle, Senior Medical Officer at the Department of Health who was well aware of the urgent need of organ donors from Afro-Caribbean and Indo-Asian ethnic minorities as they have the biggest problems. He felt that there were increasing problems because of the numbers from these minority groups in renal dialysis units. Again, the issue of the lack of data arose. Although he stated that they do not have enough data about the Indo-Asian community, he suggested that there are no donors from Indo-Asians because they preferred to die at home:

> *We are currently trying to research whether they come to the hospital at all in the first place? Some say that if they get a severe illness like stroke they do not come to the hospital, they are managed at home and died there. We do not have evidence as to whether this is true or not, it is just something we are told. We are funding a campaign to start looking at this issue.*

However, he supported the same point that was made by researcher two about late diagnosis:

> *When a person from the Indo-Asian community comes to the hospital, they often have pathology such as a stroke that is worse than seen in other communities. So when they do come to the hospital, they often are to be too sick to be referred to ITU.*

However, he stressed that they do not have any formal data supporting this suggestion.

> *At the moment we trying to commission research looking to whether any of these theories have any truth in them at all. But what is true is that this population are under-represented on ITUs.*

I asked him how the Government approaches Indo-Asian communities. He stated that they did a lot of research with groups to find out how to get the message across effectively. They have produced publicity material and frequently had advocates appear on Asian media, such as local radio, telling the community that they have to be part of the solution. They have always employed agents from the appropriate cultural background. However, when asked to comment on the fact that leaflets still used general statements and did not distinguish between religious backgrounds and sub-ethnic groups. He said:

> *We have a very longstanding problem because they speak many different languages in different parts of the country and we have dozens of different communities. There is no way in this country with the diversity of populations that you can use a national programme. We have dozens of languages, so how you can translate our leaflet to more than hundred languages? The Indo-Asian community in Birmingham is different from Leicester, which is different from Bradford, and is different from London, because they came from different parts of the Indian subcontinent and they have different cultural backgrounds. The transplant*

units themselves in places like Bradford try to become engaged with the local community leaders. For example, Birmingham was the first one to appoint South Asian coordinator.

He added that extra money and effort is needed to deal with ethnic minority groups. He insisted that would be better if they worked with local organisations:

It takes a huge effort and a huge amount of work, and it is costly. Therefore the way we that we have structured the programme and the way we are working with organisations is to develop a number of local projects. We hope to persuade the particular local leader that organ donation is acceptable. Then, the other thing we need to do is to develop much better processes for people dying in hospital, so that, having engaged the local cultural leaders in understanding the issues of organ donation, we can then contact them in time to come and support the family.

Unlike Jane Griffiths, he was enthusiastic about the Bradford and Birmingham experiences and, when he was asked about the most effective way to address the issue of organ shortage for Muslim Indo-Asians, he stated that various strategies had been adopted to create greater awareness of organ donation. There should be a national conference which would bring together diverse interested parties including religious leaders of the major faiths, clinicians and health care professionals, and policy makers to discuss and debate moral and religious perspectives on organ donation. This conference is held yearly under the title of "Organ Donation and Transplantation- the Multi-Faith perspective". He hoped that UK Transplant would respond by doing something about publicity:

The primary role of the Department of Health is to implement government policy towards arranging the services including organ donation and transplantation. Government's role is primarily to try to set a framework in which organ donation and transplantation is established. It is very important that this is based on evidence of effectiveness. The large part of the role of transplant team here at DoH is to examine experiences in organ donation both here and abroad to try and learn what is effective and what is not effective and then advise the Government, the NHS and society on what is likely to work to maximise organ donation and transplantation. So our job is largely analytical.

In response to a question regarding the insufficiency of campaigning and distributing leaflets among the Indo-Asians community, he said that he thought it was "useless":

No. It does not work like that. We know from a lot of other research that you need to talk face to face to discuss with people to get them to understand the issues and to get them to agree that organ donation is good thing. All in all to do that you need to engage with the cultural leaders, the local people, and discussion groups.

However, he was very optimistic about educating the new generation of Indo-Asians. He felt that might be work, especially as they speak English:

We have very little evidence to show that it will improve organ donation rates. But organ donation refusal rates among many of these communities are as high as seventy per cent. We do not think we can do much worse. We think that if we can practically engage the younger elements, the ones who do speak English, so they understand the issue through the media, films, advertisements and at the same time educating the cultural

leaders who will be able to discuss these issues with the older men in the population, we might be more successful.

He was disappointed when showed the findings of the current study:

We are frustrated because this is the problem we have had engaging with the leaders. Clearly we have got a much bigger job to do in engaging with Imams and all the mosques. The trouble is if you going to engage with every community it take years. We do not have enough time.

However, he suggested applying the same approach as outlined in this study in other places that have larger Indo-Asian communities.

In Birmingham, they worked very hard with local South-Asian communities. It would be very interesting to see wither the local Imams in Birmingham have the same views as the Imams in London where there has not been any local activities. Comparing London where there has been no engagement effectively, Birmingham where there has being long term engagement, and Bradford has been has been medium inter-engagement, might be very interesting. The sort of work you are doing is going to be valuable for filling in the picture but I would like to compare the experiences in London particularly with Birmingham.

In response to a question about changing the system of donation into "opting-out", he stated that one of the reasons why "opting-out" is less relevant is because of the threat of HIV and other infections; a full medical history has to be taken. If, during questioning, relatives object, organs are not retrieved whatever the legal position, for fear of adverse publicity. However, he argued that a survey showed that only twenty-five per cent of the population were in favour of an "opting-out" and the system could not be changed without public approval.

If you are screening your donors and any relative objects to organ donation, you will not take the organ because of bad publicity. In every country in the world where there is a free press and bad press about organ donation it always lead to an increase in refusal to donate. So no country, even those using presuming consent, risk adverse publicity for organ donation. France had it in mid nineties and showed a drop of 30 % in donation rates. It took three years to get back to previous levels. Think about the number of people who could not treated in that time because of one story in the press. We had the same in the eighties in the UK on account of one very badly made television programme. So the law, presumed consent, opting-in, and opting-out, are irrelevant, unless you are going to risk transplanting unsafe organs that you have retrieved from anyone who dies.

6.5 Current legislation in the UK

At present in the UK, the "opting-in" system for organ donors operates and consent from the next of kin is essential before the retrieval of organs takes place. There are two Acts of Parliament concerning organ donation and transplantation: the Human Tissue Act 1961 and the Human Organ Transplant Act 1989. The first act regulates a person's wish to provide his body or any part of it to be used after his death for "therapeutic, educational and research purposes", while the second one was a response to the trade in organs. The Department of Health established a number of regulatory bodies to control how organs are used. This included the establishment of the Unrelated Live Transplant Regulatory Authority (ULTRA).

Although brain stem death is generally accepted today, there is no statutory definition of death in UK law. Death has traditionally been defined by "cardio-respiratory criteria". The Criminal Law Revision Committee (1980) rejected a statutory definition. They argued that it would amount to fixing an expression of present opinion and could become outdated. They also found disagreements as to the scope of such a definition. Jennett (1977) argued that a statutory definition was necessary to protect health care professionals from facing criminal charges.

Furthermore, none of these laws defined who is the person lawfully in possession of the body who can make the donation decision. The Human Tissue Act 1961 mentions in Section One and Two that organs from the deceased maybe used if removal was authorised by the person who is lawfully in possession of the body. This Act does not identify who this person is. On the other hand, while the deceased's relative could object to a decision to donate, the Human Tissue Act Section Seven allowed the hospital or nursing home where the deceased was treated or resident to have control of his body. Although the 1961 Act states that a person should have made his wishes known in advance verbally or in writing, there is no age limit stipulated for such a declaration. None of these laws takes in account the religious background to a person. They do not even consider an organ donor card as an advance directive of what the person concerned wished to happen to them when they were no longer in a position to decide for themselves. The next question therefore to be raised is what action should be taken for those who have no next of kin.

As found from the interviews, a number of health care professionals are in favour of providing financial incentives. However, the Human Organ Transplant Act 1989 makes it an offence to use any payment when dealing in human organs. It has been argued that these laws are not up-to-date. These Acts might impose certain limitations on personal and economic freedom. However, the issue of conditional donation is not mentioned in any of these Acts.

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Part III

Discussion and implications of the study

Chapter 7

The role of religion in the attitude of the UK Muslim Indo-Asian community to organ donation

7.1 Summary and conclusion

Although the medical development of surgical techniques for organ transplantation which may be similar everywhere in the World, diverse cultures and religious views regarding the body, differences in resources, and the policies that regulate health care services all influence the rate at which organs are donated from different ethnic minorities in various ways. This may be because organ transplantation is a branch of medicine that has brought new ways of understanding death, human rights, commerce, gift giving, and ethics (Daar & Marshall, 1998). Santiago-Delpin (1997) argued that the problem of the shortage of organs for donation constitutes a "public health crisis".

Jakubowska-Winecka (1998) argued that increasing organ donation for transplantation would depend on generating a positive attitude towards it within the general public. However, it has been argued that the shortage of organs is not due to a lack of donors, but rather to a failure to turn many potential donors into actual donors. Thomas (1992) indicated that organ transplantation has became one of the most sociologically intricate and highly charged forms of treatment in modern medicine, where human values, beliefs and concerns are just as important as the treatment itself.

In recent years, many parts of the world have experienced difficulty in recovering organs from their ethnic minority populations. Transplant professionals devote considerable resources to educating their minority communities about the shortage of organ donors, as well as the need for organ donation. Toledo-Pereyra (1992) argued that organ donation from ethnic minority groups is both "serious and complex". He stressed that problems arise because of "misunderstandings" by members of the groups, making it difficult to offer appropriate education and support.

Ahmad (1992) argued that policies underpinned by the principles of "multiculturalism" have emphasized that services should take greater account of the cultural needs of people from different ethnic backgrounds, and have led to calls for cultural awareness training to be included in the education of health care professionals. At the same time, Samaje (1995) argued that the emphasis on the specific cultural needs of minority ethnic communities has diverted attention away from the significance of racism and socio-economic disadvantage. However, Ahmad (1992) stated that although recent health policy makes reference to combating individual racism and addressing inequalities in health, it is too early to judge what impact these directives may have on addressing the health discrimination and disadvantages experienced by people from minority ethnic communities.

In the past decade, ethnic diversity has become an important consideration in the development of health care services in the UK. Approximately 6% of the United Kingdom population has an ethnic minority background. However, ethnic minority populations are not evenly distributed but, rather, are concentrated, in certain areas, particularly the large urban conurbations in England where the proportion of the population from minority ethnic groups may exceed 40% (Office of Population Censuses and Surveys, 1991). It is argued that existing health care provision frequently falls short of meeting the health needs of minority ethnic communities such as Indo-Asians (Ahmad, 1992; Smaje, 1995).

The current shortage of organs for transplantation among the Indo-Asian community is a matter of considerable concern for health care professionals in the UK, because of the increased incidence of diabetes and hypertension with end-stage renal failure in this ethnic group. It has been described as an epidemic amongst Asians living within the UK. Indo-Asian communities have a culture, life style, language and religion that differ not only from the majority Caucasian population, but also between one community and another.

The literature suggests that there seems to be a common belief among health care professionals that members of the Indo-Asian community are less likely to agree to transplantation. Within the Islamic faith, there appears to be some degree of ambivalence on this issue. Whereas a fairly permissive attitude prevails among many Muslim Indo-Asians themselves, views among Islamic religious leaders in the Indian subcontinent are often rather more hostile to organ transplantation (Gatrad, 1994). In an attempt to rectify this deficit, recent health policy has made explicit reference to the importance of health services responding to ethnic diversity in British society (Department of Health, 1992; Balarajan & Raleigh, 1993; NHS Ethnic Health Unit, 1996; Department of Health, 1997).

In February 1999, the Government launched the South Asian Community Campaign, working closely with representatives from the community. The Department of Health has invested £250,000 in a three-year campaign to promote organ donation from the Indo-Asian community (Ashraf, 1999). However, it seems that this campaign has not met with much success. Unfortunately, there is no single study that shows the outcome of this campaign.

Although Indo-Asian attitudes to organ donation have been studied in many cities in the UK, few studies have investigated the attitudes of Muslim Indo-Asians in London. Muslim Indo-Asians represent Britain's largest ethno-religious minority, with numbers estimated at about 1.5 million. Nevertheless, Muslims have not yet been studied in any consistent fashion. Thus, for the purpose of this study an attempt has been made to focus on British Muslim Indo-Asians. Studying Muslim Indo-Asian beliefs and attitudes and identifying issues and barriers can help to inform ways to increase organ donation, which increase is urgently needed for the benefit of potential organ recipients from the same community. Whilst a number of studies have investigated the attitude of the Indo-Asian community in general, I believe that this research study is the first to take a close look at the attitudes of Muslim Indo-Asians from different perspectives.

I also feel that the choice of research design and methods was reasonably successful. The influence of "grounded theory" as a qualitative methodology adapted for this research study is vindicated by the depth of exploration that it has made possible. Although it falls short of developing theory, this study had developed different perspectives among the participants. It offers richly descriptive data on Muslim Indo-Asians' perceptions, attitudes, beliefs, views and feelings. This is obviously of most value when the topic or study population has not been extensively studied in the past.

It seems appropriate here to emphasise that the goal of triangulation is to strengthen the total research study, regardless of which method is chosen as the primary means of data collection. For instance, running focus group discussions gave access and insight into Muslim Indo-Asians' perceptions, which were then used to construct and interpret their attitudes. Focus group discussions lead the researcher to ask better questions, based on direct contact with the experiences and perceptions of those who participated in the study. I was able to use a small number of exploratory focus groups in the very early stages of this research to guide the later construction of the interview questions. This proved reasonably successful. The use of focus groups allowed me to gather different views on the issue under study in a short time.

The findings from this research study of a sample of Muslim Indo-Asians indicate that their attitudes are similar to findings reported in previous studies in the literature with respect to the issue of the sanctity of the human body. This study suggests participants expressed very similar concerns about organ donation. Only slight differences were detected over specific issues. The language and manner in which their concerns were verbalised often differed between the different segments of the community, based on both religion and age. Younger members of the community are more willing to donate than seniors.

Although almost all participants in this research study were aware of organ transplantation activities, most of them were not willing to donate their organs for transplantation. Although participants were currently unwilling to donate their own, or a family member's organs, this seemed to be in large measure because they believed that Islam prohibited donation. This presents a potentially anomalous contrast to their acceptance of the idea of donating blood. Having said that, the appropriate comparison for blood donation might be live organ donation, although that would fail to take account of the perceived need to maintain an intact body.

Because of the confusion and misinformation that exists about the Islamic perspective on organ donation for transplantation, participants were less likely to make a commitment to donate. They also conceded this was an issue they had given little thought to. However, participants were generally uncertain and not enthusiastic about organ donation.

Body disfigurement continues to be a significant concern to all participants. Some of them would be more willing to donate organs if they knew someone in their community who was in need of an organ transplant to survive.

Another source of concern was the knowledge that Islam does not normally allow anyone to touch a body after death. Another issue is the importance of a person's body being intact at the time of burial. Muslims stress the importance of treating the dead with complete respect and protecting bodies from disturbance or harm. They believe that there is life after death and bodies should be complete and whole for burial. It seems that therefore that religious barrier to organ donation is very significant.

Interestingly, Islamic Centres in the UK play an important role in educating Muslims in the literature of Islam. Most Muslims send their children to an Islamic Centre to learn Islamic literature from the Imams, most of who are against organ donation. Clearly, this suggests that the new generation will form a similar view, which may be difficult to change in the future. Accordingly, it has been argued that formal religious organisations

would be important agencies in any effort to educate the Muslim public about organ donation and transplantation (Horton & Horton, 1990).

Muslim Indo-Asians who participated in this research study draw on religion to support a positive self-image. This is partly because the first generation immigrants are not assimilated into British society. It has been pointed out that the experiences of discrimination acts primarily to reinforce existing ethnic ties and commitments that maintain their separate ethnic identity. Hillier and Scrivens (1986) argued that the Indo-Asian community can be divided into two categories: the assimilated, who are dispersed and absorbed into the British community, and those living in "plural accommodation", in which they retain their own culture and ethnic identity. During the participant observation phase of the research, it was found that most Muslim Indo-Asians fall into the "plural accommodation" category because most of them were strongly connected with their countries of origin and still experience their life accordingly.

Within the Muslim community, religious beliefs shape attitudes regarding all aspects of life matters. For many Muslims, traditional medicine is still an important part of their health care (Qureshi, 1990). However, it is true for any culture and society that the religious and cultural values of the indigenous population have a significant impact on the health, education and social policy which drives the health care or models of care that individual patients receive (Levin, 1994). Religion gives the criterion of judgement and motivation for behaviour, and arouses or controls specific emotions and human sympathy. It is quintessentially a social phenomenon. While religion has a private dimension, people experience religion in groups (Koenig, 1997). People profess to believe certain truths that are passed down by religious traditions, although some people believe more fervently than others. Moreover, what people profess to believe often has consequences for their behaviour. Throughout the ages, the activities of groups on behalf of their religion have placed them in conflict with other groups. Not infrequently people have done awful things in the name of religion. But religion provides motivation and legitimacy for good as well as evil. This was supported by the findings in the literature,

which suggest that religious commitment might play a role in enhancing illness prevention, coping with illness and recovery.

The findings may offer a different emphasis to those of Randhawa (1998) who believed that religious beliefs were not consistently important. Indeed, Ota (1999) also stressed that public attitudes rely on many factors other than religion. These factors include social acceptance of organ donation and transplantation, governmental support, and centre(s) to coordinate organ donation, as well as religious factors. The Saudi Arabian experience proves the importance of these factors and represents a model for other countries in the Islamic World. Currently, Saudi Arabia has the largest cadaveric transplantation programme in the Muslim World (Shaheen and Souqiyyeh, 2000).

On the final issue of what does constitute the "true" Islamic perspective on organ donation and transplantation, the issue is not totally clear. Although organ transplantation is not mentioned in the *Qur'an* or in the works of Muhammad, Muslims are required to protect their health, just as society is obliged to preserve itself against disease, and further, to furnish positive health measures in their modern sense. Islam places an emphasis on promoting good health, and preventing disease. There are numerous laws, rules and recommendations for this purpose in the *Shariah*. Although Muslim scholars reason from the *Shariah* principles that Muslim should seek medical treatment, there is a clear conflict of views between different groups of scholars as to how these principles should be applied to organ donation.

From the review of the health guidelines in the *Qur'an*, it is clear that Islam encourages mankind to maintain their health and to accept treatment when they are ill. Indeed, the *Qur'an* indicates that coping with illness is an obligation for society. Furthermore, there are exceptions from the otherwise stringent rules of Islam for people suffering illness and those with special needs. Medical treatment of disease is not only a right but also an obligation in Islam. A sick person is obliged to seek treatment. There are many verses in the *Qur'an* and in the works of Muhammad that encourage Muslims to seek medical

treatment. Islam does not prescribe that a Muslim should avoid the use of a new medicine simply because Muhammad did not use it, since it did not exist in his time.

Islamic teaching also encourages health promotion and disease prevention. It encourages life-saving medical treatment for all diseases and regards the saving of life as a noble act. According to *Shariah*, humans have a major obligation to safeguard and maintain their bodies, which are entrusted to them by God in order that they may serve Him. However, it is clear now that almost all senior Islamic scholars are in favour of organ donation and support any move towards developing activities, having a clearer understanding of how brain death is determined. Being able to recognize that the criteria for brain death differ from the cardiopulmonary criteria used to determine death may be the first steps in eliminating the confusion and misconceptions often associated with brain death (Appendix 1).

Within Muslim Indo-Asian communities a large numbers of people have little or no education. The health system and ways of accessing services also differ from country to country around the world. This lack of education and knowledge of systems is compounded by the barriers of language, and of racial, cultural and religious issues that affect the uptake of any services. Additionally, there is often a lack of basic understanding of the NHS and how it works practically with respect to organ donation. Thus, targeted campaigns are needed.

In conclusion, my work on the attitudes of the UK Muslim Indo-Asian community can be summarised as follows:

1) Muslim Indo-Asians are aware of the existence of organ donation for transplantation purposes in the UK.
2) Islamic law is supportive of organ donation for transplantation for the cure of end-stage organ failure, although some scholars do not agree.
3) There is dissonance between the facts of Islamic law and public perceptions.
4) There is a lack of correct information from Islamic literature regarding the permissibility of organ donation in Islam.
5) Five main themes emerged, all of which constitute important barriers to encouraging organ donation within this population group: sacredness of the body, fatalism, and organs as a witness, recipient probity, and premature declaration of death.
6) Muslim scholars play a crucial role in a Muslim's life and must be an important focus in attempts to promote organ donation by correcting misconceptions and encouraging a faithful interpretation of religious teachings on this subject.
7) Health care professionals are in favour of changing UK law and health policies to allow more flexibility in order to increase the organ donor pool.

7.2 Recommendations

The key recommendation arising out of this study is the need for further research within the Muslim Indo-Asian community to help to identify any other factors that are important in organ donation. The findings from this study suggest that religion plays an important role for nearly all the participants from this community. Those who are unwilling to donate may be able to have their current attitudes changed and become willing donors, but the key role of local Muslim scholar or Imams as opinion-formers must be recognised. They must be empowered to take responsibility for playing a major role in the solution to the problem of organ donor shortage. It may therefore be useful, in order to encourage Muslims to donate their organs, to arrange a national conference of Muslim scholars to discuss the Islamic perspective on organ donation, and to highlight the experiences of

many Muslim countries, especially Saudi Arabia. It may also be useful if they were to share thoughts and suggestions with non-Muslim scholars.

Then, following on from this meeting, a unified *fatwa* could be released include addressing relevant concerns in regard to: the definition of death, xenotransplantation, sacredness of the body, body ownership, fatalism, organs acting as "witnesses", recipient probity, living donation, legality of an organ donor card, organ trading, and donating organs for non-Muslims. Since the Muslim Law Council in the UK has already covered almost all of these issues in its *fatwa,* it may form the starting point of this meeting following which a new version could be issued.

Thereafter, this information could be disseminated via the Islamic Centres to the Muslim Indo-Asian community in particular. The unified *fatwa* should be provided in print signed by scholars to Islamic Centres for their congregants and for staff who work with Muslim communities. The Friday sermon and evening classes would provide ideal settings in which to address this issue. Collaboration with Islamic centres to increase awareness of donation and transplantation is vital. These collaborative efforts could be mutually beneficial and cost-effective. Furthermore, it will increase trust of the NHS and health care professional.

It is important to keep the population well informed and motivated by local scholars. The *fatwa* from the Islamic Law Council and the campaign promoting organ donation among the Indo-Asian community, organised a national level in 2000 by the Department of Health, seems to have been largely ineffective. The decision taken to invite Dr Zaki Badawi to represent British Muslims in the conference "Organ donation and transplantation – The multi-faith perspective" was inappropriate. This is because his work is not regarded as authoritative by most of Muslim Indo-Asian. He is an Arab and most Muslim Indo-Asians rely on scholars from their own countries of origin. They need a local scholar to address this particular issue on account of its sensitivity.

This was clearly indicated by the fact that none of participants in this study had heard about the *fatwa* issued by the Islamic Law Council. In this context, there is clearly a need to provide comprehensible information, and for the development of religiously appropriate support systems. Furthermore, as significant as the message is the messenger who delivers it must be from within the same community. Thus, transplant coordinators (supporting both live and cadaveric donation) should themselves be Muslim Indo-Asians. UK Transplant should make a concrete effort to address this issue directly, perhaps with the help of the Islamic Centres.

However, further research might also be needed, focussing on how best to convey this important information and increase the effectiveness of public campaigns. As Shaheen (1999) recommended, local Imams should be educated to support donation campaigns.

The media should always be used to promote awareness by highlighting the issue of organ shortage among the community. Providing religiously sensitive messages that the Muslim Indo-Asian community can easily understand is crucial. Targeted messages should revolve around the successes of transplantation, profiling people from the same community who are on the waiting list and providing clear explanations for why some patients have to wait sometimes many months or even years for a transplant. A dedicated religious scholar should develop the message, thus encouraging the Muslim Indo-Asian community to become involved from the very beginning is imperative.

It is important that Muslim Indo-Asians participate in the planning stages of future campaigns and the implementation of activities within their community. Collaboration by UK Transplant with Muslim scholars who share their mission of increasing donation and transplant awareness is vital. Shaheen (1999) stressed that it is important to have media campaigns based on Islam to encourage Muslims community in the West to donate their organs.

Health care professionals have a key role in delivering information but gaps in cultural understanding, a lack of training, limited access to language support and a lack of relevant resources have hindered such communication. Therefore, UK Transplant and local transplant coordinators should recruit Muslim Indo-Asian coordinators to implement and manage programmes designed to increase organ donation from the Muslim Indo-Asian community. They must be well versed in Islamic literature. Religiously sensitive approaches toward Muslim Indo-Asian families demonstrating appropriate respect will bring about a greater rate of acceptance. However, in all this it is important to remember, as Randhawa (1998) pointed out, the best strategy to reduce the prevalence of end-stage renal failure within the Indo-Asian community is through early diagnosis. Accordingly, it is crucial to educate them to manage risk factors such as diabetes and hypertension aggressively.

Because the make-up of each community may be different, what may be effective in one community may not be effective in another. It is very important that community members work together to educate themselves and cooperate with the health establishment in the most effective way possible. Moreover, time must be found for meaningful dialogue between health care professionals and local Muslim scholars. Attitudes are shaped by information conveyed by the mass media together with the individual experiences of people within the health care establishment.

GPs and other health care staff are encouraged to discuss organ donation with the public in general and with ethnic minority communities in particular. A proactive donor detection program performed by well-trained local transplant coordinators, the introduction of systematic death audits in hospitals, and the combination of a positive social atmosphere with adequate economic reimbursement for the hospitals have been successful in other health care systems. It is something we should aim to reproduce in the UK. Further success could be achieved by appropriate education and by increasing the awareness of both health care professionals and the public about the Muslim community. In the field of organ transplantation, the systematic study of social and

ethical aspects of organ donation is as important as work on the specific medical aspects of transplantation.

Organ transplant law and policy should be adapted to reflect the new structure of the British community. It seems that the Human Tissue Act 1961 and Human Organ Transplant Act 1989 have, in some respects, inhibited transplantation activity. In addition, the status of an organ donor card as an official testament by the deceased should be recognised; no one should be able to countermand it.

The application of a "presumed consent" approach alone in those European countries that have adopted it has not generated an increased availability of organs. Furthermore, the effect of "presumed consent" in practice is affected by a series of other factors such as the unwillingness of transplant professionals to go against the wishes of relatives. However, as has been suggested by a number of health care professionals, the issue of a trade in organs (commercialism) should be considered together with the very real concerns regarding the risks of disease transmission. The only question that remains unclear is whether this should be included in legislation. It may indeed be the case that financial incentives will generate an enhanced organ supply. A policy of reimbursing has been successfully applied in Pennsylvania, USA, where they offer financial incentives for organ donation (Charatan, 1999).

7.3 Study limitations

This study is no different from any other research in having its own methodological defects. Although limited to a small sample of Muslim Indo-Asians, I believe it has significant implications for professional practice in the field of organ donation and transplantation in general. Such findings may be important in designing future strategies. This study was carried out in a single area with a unique racial and ethnic composition. This must be taken into account in the interpretation of the results. In view of the limited scale and scope of this study, the findings may not be generalised to the whole Muslim Indo-Asian community in the UK.

Further study is needed to investigate whether other Muslim Indo-Asian communities hold similar attitudes and perceptions. The sampling techniques used could have led to bias in that some of the selected Islamic Centres could have had a particular focus on religious practice. One hundred and forty one participants are never going to be wholly representative of the one and a half million Muslim Indo-Asians living in the UK. However, it is significant that the relative uniformity of the data and the ease with which saturation was achieved suggests that these are important issues for a significant number of people. It is hoped that the random selection will have minimised any bias. In addition, the aim of conducting qualitative research is not to produce a representative sample, but to deepen the understanding of a social phenomenon.

The data collection and analysis in this study has been performed by me, which raises the additional anxiety that I have been systematically "blind" to certain phenomena or exaggerated others as a result of my own perspective. The role of Islamic Centres in this country is completely different from that experienced in Kuwait. It is to be hoped that the influence of the "grounded theory" approach, the use of several different methodological approaches, plus a substantial investment of time and energy in the field will have minimised this potential problem.

Having said that, I sensed that both the administration and congregants of the Islamic Centres were anxious about the nature of the study, especially following the events of 11 September 2001. Despite some participants' reluctance, it was possible to become involved with them.

At the end of every session, personal views were exchanged (about the research) on the Islamic perspective on organ donation. Many of the participants promised to read further about the issue and to discuss it with his/her family. I found it easy to approach the men in this community especially through their Imams. By contrast, it was difficult to access the women because of their shyness and reluctance to indulge in conversation with men.

Very little information is available to assist health care professionals in understanding the barriers to organ donation among Muslim Indo-Asians. However, the shortage of organs for transplantation in this community in the UK has now reached a critical stage. This study points to the need for large, rigorously conducted interventionist studies to determine the characteristics of successful organ procurement programmes among ethnic minorities. These studies would provide guidance to policy makers and health care professionals as they attempt to increase the numbers of organs available for transplantation. It hope that this work will contribute to alleviating what is a real problem associated with real human misery.

References

Abbud-Filho, M.; Ramalho, H.; Pires, H.S.; and Silveira, J.A. (1995). Attitudes and awareness regarding organ donation in the Western region of Sao Paulo, Brazil. *Transplantation Proceedings, 27, 1835.*

Abdalati, M. (1975). *Islam in focus*. The Islamic Centre, London.

Abelson, R.P. (1972). Are attitudes necessary? In: King, B. and McGinnies, E. *Attitudes, conflict, and social change*. Academic Press, New York.

AboZahrah, M. (1958). *Usul al fiqh*. Dar Alfeker Alarabi, Cairo.

Abu Dawud Sulayman ibn Al-Ash ath Al-Sijistani, *Sunan Abi Dawud*. Al-Sunnah Al-Nabawiyaah. Beirut.

Ahmad, W. (1992). *The politics of race and health*. University of Bradford, Bradford.

Ahmad, K. (1999). First step towards organ transplantation in Iran. *Lancet, 354, 1802.*

Ahmed, W.; Harris, S.; and Brown, E. (1999). Attitudes to organ donation among South Asians in an English high street. *Journal of The Royal Society Medicine, 92, 626-627.*

Al-Akili, M. (1996). *Natural healing with the medicine of the Prophet.* Pearl publishing house, Philadelphia.

Alasuutari, P. (1995). *Researching culture: qualitative method and cultural studies.* SAGE Publications, London.

Al-Alwani, T.J. (1990). *Source methodology in Islamic Jurisprudence: Methodology for research and knowledge*. The International Institute of Islamic Thought, Virginia.

Al-Faqih, S.R. (1991). Public attitudes toward organ donation in KSA. *Public Health, 105, 161-162.*

Al-Gazali, A.H. (1995) *The remembrance of death and afterlife*. Islamic Texts Society, Cambridge.

Al-Hilali, M.T. and Khan, M.M. (1996) *Interpretation the meanings of the Noble Qur'an in the English language.* Darussalam Publishers and Distributors, Riyadh, Saudi Arabia.

Al-Jauziyah, I. (1999). *Healing with the medicine of the Prophet*. Translated by Abualrub, J. Darussalam Publishers, Saudi Arabia.

Al-khader, A.A. and Shaheen, F. (1999). Strategies for increasing transplantation: the Saudi experience. *Transplantation Proceedings, 31, 3278.*

Al-Mousawi, M.; Hamed T.; and Al-Matouk H (1997). Niews of Muslim Scholars on organ donation and brain death. *Transplantation Proceedings, 29, 3217.*

AlQaradawi, Y. (1999) Organ transplant. Lecture.

Al-Sharawee, S. (1997). Organ transplant from living and cadaveric. *Al-Ahram, 20348, 13.*

Al-Sukari, A. (1989). *Organ transplantation: Islamic perspective*. Aldar Almasria Publisher, Cyprus.

Anonymous (1999). The UK should adopt opt-out organ donation. *Nursing Times August 18, 95, 35.*

Anwar, M. (2000). Muslims in Britain: demographic and socio-economic position. In: Sheikh, A. and Gatrad, R. (eds.) *Caring for Muslim patients*. Radcliffe Medical Press Ltd, Oxon.

Archbold, P. (1986). Ethical issues in qualitative research. In: Chenitz, W.C. and Swanson, J.M. (eds.) *From practice to grounded theory*. Addison-Wesley, Menlo Park, California.

Asbury, J.E. (1995). Overview of focus group research. *Qualitative Health Research, 5, 414-420.*

Ashraf, H. (1999). UK Asian community targeted as organ donors. *Lancet, 353, 821.*

Astrow, A.B.; Puchalski, C.M.; and Sulmasy, D.P. (2001). Religion, spirituality and health care: social, ethical and practical considerations. *The American Journal of Medicine, 110, 283-287.*

Aswad, S.; Souqiyyeh, M.Z.; Huraib, S.; and El-Shihabi, R. (1992). Public attitudes toward organ donation in Saudi Arabia. *Transplantation Proceedings, 24, 2056-2058.*

Aviles, J.M.; Whelan, E.; Hernke, D.A.; Williams, B.A.; Kenny, K.E.; O'Fallon, W.M.; and Kopecky, S.L. (2001). Intercessory prayer and cadiovascular disease progression in a coronary care unit population: a randomised controllred trial. *Mayo Clinic Proceedings, 76, 1192-1198.*

Balarajan, R. and Raleigh, V.S. (1993). *Ethnicity and health: a guide for the NHS*. Her Majesty's Stationery Office, London.

Ball, S; Lloyd, J; Cairns, T.; Cook, T.; Palmer, A.; Cattell, V.; and Taube, D. (2001). Why is there so much end-stage renal failure of undetermined cause in UK Indo-Asians? *Quarterly Journal of Medicine, **94**, 187–93.*

Barbour, R.S. and Kitzingen, J. (1999). *Developing focus group research: theory and practice*. SAGE, London.

Basch, C.E. (1987). Focus group interview: an underutilized research technique fro improving theory and practice in health education. *Health Education Quarterly, **14**, 411-448.*

Bauchner, H. and Vinci, R. (2001). What have we learnt from the Alder Hey affair? That monitoring physicians` performance is necessary to ensure good practice. *British Medical Journal, 322, 309-10.*

Beecham, L (2000) Donors and relatives must place no conditions on organ use. *British Medical Journal, **320**, 534.*

Berry, R.J. (2000). Science and religion: friends or foes? *Science Progress, **83**, 3-22.*

Bigam, D.; Zhong, R.; Levy, G.; and Grant D. (1999). Xenotransplantation. *Canadian Journal of Surgery, **42**, 12-16.*

Bilgel, H.; Bilgel, N.; Okan, N.; Kilicturgay, S.; Ozen, Y.; and Korun, N. (1991). Public attitudes towards organ donation: a survey in Turkish community. *Transplantation Proceedings, 4, 243-245.*

Bollinger, R.R. (2001). Ethics of transplantation. In: Hakim, N.S. and Danovitch, G.M. (eds.). *Transplantation surgery.* Springer-Verlag, London.

Bolton, B.P. (2002). God, science, and intercessory prayer. *Archives of Internal Medicine, **162**, 1422-23.*

Booster, M.H.; Wijnen, R.M.; Vroemen, J.P.; Van-Hooff, J.P.; and Kootstra, G. (1993). In situ preservation of kidneys from non-heart-beating donors - A proposal for a standardized protocol. *Transplantation Proceedings, **25**, 1503-04.*

Bosch, X. (1998). Spain celebrates leading the World in organ donation. *Lancet, **351**, 1868.*

Bosch, X. (1999). Spain leads World organ donation and transplantation. *Journal of Medical American Association, **282**, 17-18.*

Bradley, J.N. and Hamilton, D.N. (2001). Organ Transplantation: an Historical Perspective. In: Hakim, N.S. and Danovitch, G.M. (eds.) *Transplantation Surgery.* Springer-Verlag, London.

British Medical Association (2000). Organ Donation in the 21st Century. www.bma.org.uk

British Transplantation Society (1998). *Towards standards for organ and tissue transplantation in the United Kingdom.* Surrey.

Brown, D. (1996). *Rethinking tradition in modern Islamic thought*. Cambridge University Press, Cambridge.

Bryman, A. (1988). *Quantity and quality in social research*. Unwin Hyman, London.

Bryman, A. and Cramer, D. (1990). *Qualitative data analysis for social scientists*. Routledge, London.

Bryman, A. (2001). *Social research methods*. Oxford University Press, Oxford.

Burroughs, T.E.; Hong, B.A.; Kappel, D.F.; and Freedman, B.K. (1998). The stability of family decisions to consent or refuse organ donation: would you do it again? *Psychosomatic Medicine, 60, 156-162.*

Chapman, L.S. (1986). Spiritual health: a component missing from health promotion. *American Journal of Health Promotion, 1, 38-41.*

Chapman, A.B.; Johnson, A.M.; Rainguet, S.; Hossack, K.; Gabow, P.; and Schrier, R.W. (1997). Left ventricular hypertrophy in autosomal dominant polycystic kidney disease. *Journal of the American Society of Nephrology, 8, 1292-97.*

Charatan, F. (1999). Pennsylvania plans to reward organ donation. *British Medical Journal, 318, 1371.*

Charmaz, C. (2000). *Grounded theory; objectivist and constructivist methods*. In: Denzin, N.K. and Lincoln, Y.S. (eds.) Handbook of qualitative research (2nd ed). SAGE publications, London.

Chenitz, W.C. and Swanson, J.M. (1986). *From practice to grounded theory*. Addison Wesley, Menlo Park, California.

Choo, V. (1995) UK Shariah Council approves organ transplant. *Lancet, 346, 303.*

Chryssides, G. (1994). Britain's changing faiths: adaptation in a new environment. In: Parsons, G. (ed) *The growth of religious diversity*. The Open University, London.

Clark, A.L. and Coats, A.J. (1993) Screening for hypertrophic cardiomyopathy. *British Medical Journal, 306, 409-10.*

Clark, T.J.; Richards, N.T.; Adu, D.; and Michael, J. (1993). Increased prevalence of dialysis-dependent renal failure in ethnic minorities in the West Midlands. *Nephrology Dialysis Transplantation, 8, 146-48.*

Clark, K.M.; Friedman, H.S.; and Martin, L.R. (1999). A longitudinal study of religiosity and mortality risk. *Journal of Health Psychology, 4, 381-91.*

Clarke, P. (1993). *Religion defined and explained.* Macmillan press Ltd. London.

Corlett, S.R. (1985). Public attitudes toward human organ donation. *Transplantation Proceedings, 20, 103-110.*

Daar, A.S. (1991). Organ donation-World experience; the Middle East. *Transplantation Proceedings, 23, 2505-2507.*

Daar, A. and Marshall, P. (1998). Culture and psychology in organ transplantation. *World Health Forum, 19, 124–32.*

Darr, A. and Randhawa, G. (1999). Awareness and attitudes towards organ donation and transplantation among the Asian population. *Transplantation International, 12, 365-371.*

Davidson, M.N. and Devney, P. (1991). Attitudinal barriers to organ donation among Black American. *Transplantation Proceeding, 23, 2531-2532.*

Davies, M.J.; Ammari, F.; Sherriff, C.; Burden, M.L.; Gujral, J.; and Burden, A.C. (1999). Screening for type 2 diabetes mellitus in the UK Indo-Asian population. *Diabetic Medicine, 16, 131-37.*

Decleration of the Organisation of the Islamic Conference-Islamic Figh Academy. (1986). Third Meeting, Amman, Jourdan.

Denzin, N.K. and Lincoln, Y.S. (2000). *Handbook of qualitative research (2nd ed).* SAGE publications, London.

Dein, S. and Stygall, J. (1997). Does being religious help or hinder coping with chronic illness? A critical literature review. *Palliative Medicine, 11, 291-98.*

Department of Health, (1999a) *Survey shows that public prefers existing organ donor sheme.* Media Centre, DoH, UK.

Department of Health, (1999b) *South Asian Community to be targeted by advertising campaign.* Media Cntre, DoH, UK.

Department of Health, (2000a) *The Review of the United Kingdom Transplant Support Service Authority 1998/99: Executive Summary.* Department of Health Publication, UK.

Department of Health, (2000b) *An investigation into conditional organ donation: the report of the panel*. The Department of Health Publication, UK.

Department of Health, (2001). *Organ retention-further guidance*. The Department of Health Publication, UK.

Department of Health, (2002a) *Be part of the solution.* The Department of Health Publication, UK.

Department of Health, (2002b) *10 million sign up to organ donation*. The Department of Health Publication, UK.

UK Transplant, (2003) *United Kingdom Hospital Policy for Organ and Tissue Donation.* The UK Transplant Publication, UK.

Dominguez, J.M.; Gonzalez, Z.A.; Morales-Otero, L.A.; Torres, A.; and Santiago-Delpin, E.A. (1991). Knowledge and attitude about organ donation in a Hispanic population. *Transplantation Proceedings, 23, 1804-1806.*

Donnelly, P.K.; Simpson, A.R.; Oman, P.; Horsburgh, T.; Feehally, J.; Walls, J.; Veitch, P.S.; and Bell, P.R. (1992). Is Indian origin a risk factor in cadaveric renal transplantation? *Transplantation Proceedings, 24, 1759.*

Dossey, L. (1995). *Healing Words: the power of prayer and the practice of medicine.* Harper, San Francisco.

Eagly, A. and Chaiken, F. (1993). *The psychology of Attitudes*. Harcourt Brace, Fortworth.

Eaton, G. (1999) *Islam and the destiny of man.* The Islamic text society. Cambridge.

Ebrahim, A.F. (2001) *Organ transplantation, Euthanasia, chining, and animal experimentation: an Islamic view*. The Islamic Foundation, Kenya.

Economist. (1996). Economic and financial statistics on 15 OECD countries plus closer looks at commodities, health spending and big companies. *23, 340.*

Ehman, J.W.; Ott, B.B.; Short, T.H.; Ciampa, R.C.; and Hansen-Flaschen, J. (1999). Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Archives of Internal Medicine, 159, 1806-09.*

Eisenberg, D.M. (1998). Trends in alternative medicine use in the United State. *Journal of American Medicine Association, 280, 1569-75.*

El-Kadi, A. (1993) Health and Healing in the Qur'an. In Islamic perspective in medicine. In: Athar, S. (ed.) *A survey of Islamic medicine: achievements and contemporary issues.* American Trust Publications, Indianapolis.

El-Shahat, Y.M. (1999) Islamic viewpoint of organ transplantation. *Transplantation Proceedings, 31, 3271-3274.*

Endress, G. (1988) *An introduction to Islam.* Edinburgh University Press, Edinburgh.

European Transplant Coordinators Organisation (ETCO) (2001). *Organs and Tissues, 4, 5–7.*

Evans, R.W. and Kitzmann, D.J. (1998). An economic analysis of kidney transplantation. *The Surgical Clinics of North America, 78, 149–74.*

Exley, C., Sim, J.; Reid, N.G.; Booth, L.; Jackson, S.; and West, N. (1996). The admission of Asian patients to intensive therapy units and its implications for kidney donation: A preliminary report from Coventry, UK. *Journal of Epidemiology and Community Health. 50, 447-50.*

Exley, C.; Sim, J.; Reid, N.; Jackson, S.; and West, N. (1996). Attitudes and beliefs within the Sikh community regarding organ donation: a pilot study. *Social Sciences and Medicine, 43, 23-8.*

Fielding, N.G. and Fielding, J.L. (1986). *Linking data: the articulation of qualitative and quantitative methods in social research.* SAGE, Beverly Hills.

First, M.R. (1997). Controversies in organ donation: minority donation and living unrelated renal donors. *Transplantation Proceedings, 29, 67-9.*

Fishbein, M. and Allport, G. (1967). *Reading in Attitude theory and measurement.* John Wiley & Sons, New York.

Flick, U. (1998). *An introduction to qualitative research: theory, method, and applications.* SAGE Publications, London.

Fontana, A. and Frey, J.H. (1994) Interviewing: the art of science. In: Denzin, N.K. and Lincoln, Y.S. (eds.) *Handbook of qualitative research.* SAGE Publications, London.

Forward, M. (1994) Islam in Holm. In: Bowker, J. (ed.). *Human nature and destiny.* Pinter, London.

Gabel, H. and Lindskoug, K. (1988). A survey of public attitudes toward cadaveric organ donation in a Swedish community. *Transplantation Proceedings, 22, 431.*

Gatrad, A.R. (1994) Muslim customs surrounding death, bereavement, post-mortem examinations, and organ transplant. *British Medical Journal*, ***309***, 521-23.

Gibbs, A. (1998). Focus groups. *Social Research Update, **19**, 1-7.*

Glaser, B.G. and Strauss, A.L. (1966). *Awareness of dying*. Aldine Publishing Company, New York.

Glaser, B. and Strauss, A. (1967). *The discovery of grounded theory: strategies for qualitative research.* Aldine Publishing Company, New York.

Glaser, B. (1978). *Theoretical sensitivity*. Sociology Press, Mill Valley, California.

Glaser, B. (1992). *Emergency vs. forcing: basic of grounded theory analysis: emergency versus forcing*. Mill Valley, California.

Glass, T.A., Mendes de Leon, C., Marottoli, R.A., and Berkman, L.F. (1999). Population based study of social and productive activities as predictors of survival among elderly American. *British Medical Journal, **19**, 478-83.*

Goldman, N.; Korenman, S.; and Weinstein, R. (1995). Marital status and health among elderly. *Social Sciences and Medicine, **40**, 1717-30.*

Gove, P.B. (1961). *Webster's third new international dictionary of the English language*. Springfield, mass: G and C Merriam, Unabridged.

Guadagnoli, E; McNamara, P; Evanisko, M; Beasley, C; Callender, C; and Poretsky, A. (1999). The influence of race on approaching families for organ donation and their decision to donate. *American Journal of Public Health, **82**, 244-47.*

Hakim, C. (1987). *Research design: strategies and choices in the design of social research*. Routledge.

Hakim, N.S. (1997). *Introduction to organ donation*. Imperial College Press, London.

Hakim, N.S. and Danovitch, G.M. (2001). *Transplantation Surgery*. Springer-Verlag, London.

Hall, L.E.; Callender, C.O.; Yeager, C.L.; Barber, J.B.; Dunston, G.M.; and Pinn-Wiggins, V.M. (1991). Organ donation in blacks: the next frontier. *Transplantation Proceedings, **23**, 2500-04.*

Hamilton, D.N. (1984). Yu Yu Voronoy and the first human kidney allograft. *Surgery of Gynecology and Obstetrics, **159**, 289-94.*

Hammersley, M. (1989). *The dilemma of qualitative method.* Routledge, London.

Hassaballah, A.M. (1996). Definition of death, organ donation and interruption of treatment in Islam. *Nephrology, Dialysis, Transplantation, 11, 964-965.*

Hassan, H. (1997). llusion of treatment by transplant. *Al-Akhbar, **14050**, 33.*

Hastings, J. (1971). *Encyclopadia of religion and ethics, Vol,10.* T and T Clark, Edinburgh.

Hillier, S.M. and Scrivens, E. (1986). Ethnicity, health, and health care. In: Patrick, D.L. and Scambler, G. (eds.) *Sociology as applied to medicine* (2nd ed.). Bailliere Tindall, London.

Hixson, K.A.; Gruchow, H.W.; and Morgan, D.W. (1998). The relation between religiosity, selected health behaviours, and blood pressure among adult females. *Preview Medicine, 27, 545-52.*

Holland, J.C.; Kash, K.M.; Passik, S.; Gronert, M.K.; Sison, A.; Lederberg, M.; Russak, S.M.; Baider, L; and Fox, B. (1998). A brief spiritual inventory for use in quality of life research in life threatening illness. *Psycho-oncology, 7, 460-69.*

Homan, R. (1991). *The ethics of social science research.* Longman, London.

Horton, R.L. and Horton, P.J. (1990). Knowledge regarding organ donation: identifying and overcoming barriers to organ donation. *Social Science and Medicine, **31**, 791–800.*

Hummer, R.A. (1999). Religious involvement and U.S. adult mortality. *Demography, **36**, 273-85.*

Ibrahim, I.A. (1997) *A brief illustrated guide to understanding Islam.* Darussalam, Huston.

Idler, E.L.; Kasl, S.V.; and Wilcox, V.L. (1997). Religion among disabled and nondisabled person. *Journal of Gerontology and Behaviour Psychology and Sciences of Sociology, 52, S306-S316.*

Jakubowska-Winecka, A. (1998). Psychological rules of communication with relatives of a potential organ donor: the Polish experience. *Annals of Transplantation, 3, 42–5.*

Johnson, L.W.; Lum, C.T.; Thompson, T.; Wilson, J.; Urdaneta, M.L.; and Harris, R. (1988). Mexican-American and Anglo-American attitudes toward organ donation. *Transplantation Proceedings, 22, 822-823.*

Jones, R.K. (1975). *Sociology in Medicine.* The English Universities Press Ltd, London.

Joun, Y.; Coonan, P.R.; and LeGrande; M.E. (1997). Attitudes of Korean-Americans in and around New York city toward organ transplantation. *Transplantation Proceedings, **29**, 3751-3752.*

Kamali, M.H. (1991). *Principles of Islamic jurisprudence*. The Islamic Texts Society, Cambridge.

Kidney transplantation (1999). The Hammersmith Hospital NHS Trust, Leaflet.

King, D.E. and Bushwick, B. (1994). Beliefs and attitudes of hospital inpatients about faith healing and prayer. *Journal of Family Practice, **39**, 349-352.*

Kitzinger, J. (1995). Introducing focus groups. *British Medical Journal, **311**, 299-302.*

Kmietowicz, Z. (1999). More doctors and donors needed for transplantation in the UK. *British Medical Journal, **318**, 7180.*

Kobryn, A. and Modiba, M.C. (1998). Attitudes of black South Africans concerning organ donation. *Journal of Transplant Coordination, 8, 241-2.*

Koenig, H.G.; Larson, D.B.; Hays, J.C.; and Idler, E. (1998). Religion and the survival of 1010 hospitalised veterans. *Journal of Religion Health, 37, 15-29.*

Koenig, H.G.; George, U.K.; Hays, J.C.; Larson, D.B.; Cohen, H.J.; and Blazer, D.G. (1998). The relationship between religious activities and blood pressure in elder adults. *International Journal of Psychiatry Medicine, **28**, 189-213.*

Koenig, H.G. (1998). Use of hospital services, religious attendance and religious affiliation. *South Medical Journal, **91**, 9250932.*

Koenig, H.G.; McCullough, M.E.; and Larson, D.B. (2001). *Handbook of religion and health*. Oxford University Press, New York.

Koenig, H.G. (2002). Spirituality and chronic illness. *The Journal of the American Medical Association, **288**, 2542.*

Koffman, G. and Gambaro, G. (2003). Renal transplantation from non-heart- beating donors: a review of the European experience. *Journal of Nephrology. **16**, 334-41.*

Kootstra, G.; Daemen, J.H.; and Oomen, A.P. (1995). Categories of non-heart-beating donors. *Transplantation Proceedings. 27, 2893-94.*

Koppiker, N.; Feehally, J.; Raymond, N.; Abrams, K.R.; and Burden, A.C. (1998). Rate of decline in renal function in Indo-Asians and Whites with diabetic nephropathy. *Diabetic Medicine, 15, 60-5.*

Kruger, R.A. (1994). *Focus groups: a practical guide for applied research (2nd ed).* SAGE Publications, London.

Kyriakides, G.; Hadjigavriel, M.; Hadjicostas, P.; Nicolaides, A.; and Kyriakides, M. (1993). Public awareness and attitudes toward transplantation in Cyprus. *Transplantation Proceedings, 25, 2279.*

Lanciani, C.A. (2002). Must science and religion be separated? *Archives of Internal Medicine, 162, 1421.*

Leibovici, L.P. (2002). Effect of retroactive intercessory prayer: author's reply. *British Medical Journal, 324, 1038-39.*

Levin, J.S. and Vanderpool, H.Y. (1987). Is frequent religious attendance really conducive to better health? Toward an epidemiology of religion. *Social Science & Medicine, 24, 589-600.*

Levin, J.S. and Vanderpool, H.Y. (1989) Is religion therapeutically significant for hypertension? *Social Science & Medicine, 29, 69-78.*

Levin, J.S. (1994). Religion and health: is there an association, is it valid, and is it causal? *Social Science & Medicine, 38, 1475-82.*

Levin, J.S.; Larson, D.B.; and Puchalski, C.M. (1997). Religion and spirituality in Medicine: research and education. *The Journal of the American Medical Association, 278, 792-783.*

Lewis, B. (1993). *Islam and the West*. Oxford University Press, Oxford.

Lewis, B. and Schnapper, D. (1994). *Muslims in Europe*. Pinter Publishers, London.

Lightstone, L.; Rees, A.J.; Tomson, C.; Walls, J.; Winearls, C.G.; and Feehally, J. (1995). High incidence of end-stage renal disease in Indo-Asians in the UK. *Quarterly Journal of Medicine, 88, 191–5.*

Lincoln, Y. S. and Guba, E. G. (1985). *Naturalistic inquiry*. SAGE Publications, Beverly Hills, California.

Lip, G.Y.; Bawden, L.; Hodson, R.; Rutland, E.; Snatchfold, J.; and Beevers, D.G. (1998). Atrial fibrillation amongst the Indo-Asian general practice population: the West Birmingham atrial fibrillation project. *International Journal of Cardiology, 65, 187-92.*

Liu, Y.; Lei, H.; and Qui, F. (1997). Investigation of attitudes towards organ transplantation in young people in China. *Chinese Medical Journal, 110, 210-215.*

Lofland, J. and Lofland, L. (1995). *Analysing social settings: a guide to qualitative observation and analysis (3rd ed)*. Wadsworth Publishing Company, Bemnt, California.

Lumsdaine, J.A.; Wigmore, S.J.; and Forsythe, J.L. (1999). Live kidney donor assessment in the UK and Ireland. *British Journal of Surgery, 86, 877-81.*

Manninen, D.L. and Evans, R.W. (1985). Public attitudes and behaviour regarding organ donation. *Journal of American Medical Association, 253, 3111-15.*

Mardiros, M. (1989). Conception of childhood disability among Mexican-American parents. *Medical Anthropology, 12, 55-68.*

Marshall, P.A. and Daar, A.S. (1998). Cultural and psychological dimensions of human organ transplantation. *Annals of Transplantation, 3, 7-11.*

Marshall, C. and Rossman, G. (1989). *Designing qualitative research.* SAGE publication, London.

Martinez, L.; Trucco, C.; Vaccarezza, A.; and Rodriguez, L. (1991). Public opinion regarding organ donation in Chile. *Transplantation Proceedings, 23, 2528.*

Martinez, J.M.; Martin, A.; and Lopez, J.S. (1995). Spanish public opinion concerning organ donation and transplantation. *Medicina Clinica, 105, 401-401.*

Mason, J. (2002). *Qualitative researching (2nd ed)* SAGE Publications, London.

Matar, N. (1998). *Islam in Britain.* Cambridge University Press, Cambridge.

Matesanz, R. and Miranda, B. (2002). A decade of continuous improvement in cadaveric organ donation: the Spanish model. *Journal of Nephrology. 15, 22–8.*

Mather, H.M. and Keen, H. (1985). The Southall diabetes survey: prevalence of known diabetes in Asians and Europeans. *British Medical Journal, 291, 1081.*

May, K.A. (1994). Abstract knowing: the case for magic in method. In: Morse, J.M.(ed) *Critical issues in qualitative research methods*. SAGE publications, Newbury Park, California.

Medawar, P.B. (1944). The behaviour and fate of skin autografts and skin homografts in rabbits. *Journal of Anatomy, 78, 176-99.*

Miller, W.L.; Sgura, F.A.; Kopecky, S.L.; Asirvatham, S.J.; Williams, B.A.; Wright, R.S.; and Reede, G.S. (2001). Characteristics of presenting electrocardiograms of acute myocardial infection from a community-based population predict short-and long-term mortality. *American Journal of Cardiology, 87, 1045-1050.*

Miranda, B. and Matesanz, R. (1998). International issues in transplantation. Setting the scene and flagging the most urgent and controversial issues. *Annals of the New York Academy of Sciences. 862, 129–43.*

Miranda, B.; Naya, M.T.; Cuende, N.; and Matesanz, R. (1999). The Spanish model of organ donation for transplantation. *Current Opinion in Organ Transplantation, 4, 109–17.*

Moore, R. (1997). Current issues in renal transplantation. *Transplantation Proceedings, 29, 2714-15.*

Moray, G.; Karakayali, H.; Dermirag, A.; Bilgin, N.; and Haberal, M. (1999). Media effect on organ donation and transplantation. *Transplantation Proceedings, 31, 3284-85.*

Morgan, D.L. (1988). *Focus group in qualitative research.* SAGE, Newbury Park, California.

Morgan, D.L. (1993). *Successful focus groups.* SAGE, Newbury Park, California.

Morgan, D.L. (1995). Why things (sometimes) go wrong in focus groups. *Qualitative Health Research, 5, 516-523.*

Morgan, D.L. (1997). *Focus groups as qualitative research.* SAGE Publications, Thousand Oaks, California.

Morse, J.M. and Field, P.A. (1995). *Qualitative research methods for health professionals (2nd ed).* SAGE Publications, Thousand Oaks, California.

Moosa, E. (1993). Brain death and organ transplantation-an Islamic opinion. *South Africa Medical Journal, 83, 385-386.*

Muiesan, P. (2003). Liver transplantation from controlled non–heart-beating donors: an increased incidence of biliary complications. *Transplantation, 75,1627–28.*

Nanji, A.A. and Esmail, A.A. (1997). Islam. In: Quinn, P.L. and TaliaFerro, C. (eds.) *A companion to philosophy of religion.* BlackWell Publishers Ltd, Combridge.

New, B. (1994). *A question of give and take; improving the supply of donor organs for transplantation.* King's Fund Institute Report 18. London: King's Fund Institute.

Neumann, J.K. (2002). Research and religion. *Archives of Internal Medicine, 162, 1421.*

NHS Ethnic Health Unit. (1996). *Good practice and quality indicators in primary health care: health care for black and minority ethnic people*. NHS Ethnic Health Unit, Leeds.

Nicholson, M. (1996). Kidney transplantation from asystolic donors. *British Journal of Hospital Medicine, 55, 51–6.*

Office of Population Censuses and Surveys (1991). *Census, Local Base Statistics*. Her Majesty's Stationery Office, London.

Oleckno, W.A; and Blacconiere, M.J. (1991). Relationship of religiosity to wellness and other health related behaviours, and outcomes. *Psychological Representation, 68, 819-26.*

Oman, D.; Reed, D.; and Thoresen C.E. (1998). Religious and mortality among the community-dwelling elderly. *American Journal of Public Health, 88, 1469-175.*

Oppenheim, A.N. (1992). *Questionnaire design, interviewing and attitude measurement.* Continuum, London.

Osler, W. (1910). The faith that heals. *British Medical Journal, 18, 1470-1472.*

Ota, K. (1999) Asian Transplant Registry. *Transplantation Proceedings, 31, 205–9.*

Oxman, T.E.; Freeman, J.D.; and Manheimer, E.D. (1995). Lack of social participation or religious strength and comfort as risk factors for death after cardiac surgery in the elderly. *Psychosomatic Medicine, 57, 5-15.*

Patton, M.Q. (1990). *Qualitative evaluation and research methods (2nd ed).* Newbury Park, SAGE, California.

Perkins, K.A. (1987). The shortage of cadaver donor organs for transplantation. *American Psychologist, 42, 921-30.*

Pike, R.E.; Odell, J.A.; and Khan, D. (1992). Public attitudes to organ donation in South Africa. *Transplantation Proceedings, 24, 210.*

Rachmani, R.; Mizrahi, S.; and Agabaria, S. (2000). Attitudes of Negev Bedouins toward organ donation: a field survey. *Transplantation Proceedings, 32, 757-758.*

Radecki, C.M. and Jaccard, J. (1997). Psychological aspects of organ donation: a critical review and synthesis of individual and next-of-kin donation decisions. *Health Psychology, 16, 183-195.*

Rahman, F. (1998) Health and medicine in the Islamic tradition. ABC, Chicago.

Rajecki, D.W. (1982). *Attitudes themes and advances*. Sinauer Associates INC, Massachusetts.

Randhawa, G. (1998). An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology, Dialysis, and Transplantation, 13, 1949-1954.*

Rasheed, H.Z. (1992). Organ donation and transplantation-A Muslim viewpoint. *Transplantation Proceedings, 24, 2116-17.*

Rene, A.A.; Viera, E.; Jiles, R.; and Daniels, D.E. (1995). Organ donation awareness: knowledge, attitudes and beliefs in a Puerto Rican population. *Transplantation Proceedings, 27, 1893-96.*

Ready, A.R.; Trafford, J.; Hooker, A.; Briggs, D. (1997). Impact of a large nonindigenous population on the renal transplant waiting list. *Transplantation Proceedings, 29, 3724-25.*

Ready, A.R. (1998). Transplantation an ethnic community: approaches to the crisis. *Nephrology Dialysis and Transplant, 13, 2490-3.*

Rene, A.A.; Viera, E.; Jiles, R.; and Daniels, D.E. (1995). Organ donation awareness: knowledge, attitudes and beliefs in a Puerto Rican population. *Transplantation Proceedings, 27, 1893-1896.*

Reportage (1997). Religious leaders give organ donation a boost. *Canadian Medical Association Journal, 157, 1338.*

Rizvi, S.A. and Naqvi, S.A. (1997) Need for increasing transplant activities: a sustainable model for developing countries. *Transplantation Proceedings, 29, 1560-62.*

Roels, L.; Roelants, M.; Timmermans, T.; Hoppenbrouwers, K.; Pillen, E.; and Bande-Knops, J. (1997). A survey on attitudes to organ donation among three generation in a country with 10 years of presumed consent legislation. *Transplantation Proceedings, 29, 3224-3225.*

Rossman, G.B. and Rallis, S.F. (1998). *Learning in the field: an introduction to qualitative research.* SAGE, Thousand Oaks, California.

Rubens, A.J. (1996). Racial and ethnic differences in students' attitudes and behavior toward organ donation. *Journal of The National Medical Association, 88, 417-21.*

Quah, S.R. (1992). Social and ethical aspects of organ donation. *Transplantation Proceedings, 24, 2097–8.*

Qureshi, B. (1990). Alternative/complementary medicine. In: McAvoy, B. and Donaldson, L. (eds.). *Health care for Asians*. Oxford, University Press.

Salahi, H.; Ghahramani, N.; Malek-Hosseini, S.A.; Nezakatgoo, N.; Ahmad, E.; and Rais- Jalali, G.A. (1998). Religious sanctions regarding cadaveric organ transplantation in Iran. *Transplantation Proceeding, 30, 769-770.*

Salim, M. (1995) Medical creation of the Prophet Muhammad. Almaaref publication, Lebanon.

Samaje, C. (1995). *Health, race, and ethnicity: making sense of evidence*. King's Fund Institute, London.

Sankari, B.R.; Wyner, L.M.; and Streem, S.B. (1994) Living unrelated donor renal transplantation. *Urologic Clinics of North America, 21, 293-98.*

Sanner, M. (1994). Attitudes toward organ donation and transplantation. *Social Science and Medicine, 38, 1141-52.*

Santiago-Delpin, E.A. (1997). The organ shortage: a public health crisis. What are Latin American government doing about it? *Transplantation Proceedings, 29, 3203–4.*

Sarantakos, S. (1998). *Social research (2nd ed).* Macmillan Press LTD, Hampshire.

Schatzman, L. and Strauss, A. (1973*). Field research: strategies for a natural sociology.* Prentice-Hall, New Jersey.

Schon, M.R.; Kollmar, O.; Wolf, S.; Schrem, H.; Matthes, M.; Akkoc, N.; Schnoy, N.C.; and Neuhaus, P. (2001). Liver transplantation after organ preservation with normothermic extracorporeal perfusion. *Annual Surgery, 233, 114.*

Schutt, G and Schroeder, P. (1993). Population attitudes toward organ donation in Germany. *Transplantation Proceedings, 25, 3127-28.*

Schutte, L. and Kappel, D. (1997). Barriers to donation in minority, low income, and rural population. *Transplantation Proceedings, 29, 3746-47.*

Shafi, M. (1995) *Islam on grafting and transplanting of human organs*. Darulishaat, Pakistan.

Shaheen, F. (1999) letter. *Nephrology, Dialysis, and Transplantation, 14, 521.*

Shaheen, F.M. and Souqiyyeh, M.Z. (2000). Factors influencing organ donation and transplantation in the Middle East. *Transplantation Proceedings,* **32**, 645–6.

Sharafaldeen, A. (1983) *Islamic Law in Medical practice*. Kuwait University, Kuwait.

Sheikh, A. and Dhami, S. (2000). Attitudes to organ donation among South Asians in the UK. *Journal of the Royal Society of Medicine, 93, 161-162.*

Silverman, D. (1993). *Interpreting qualitative data: method for analysing talk, text and interaction.* SAGE, London.

Silverman, D. (1997). *Qualitative research: theory, method and practice*. SAGE Publications, London.

Silverman, D. (2000). *Doing qualitative research: a practical handbook*. SAGE Publications, London.

Siminoff, L.A. and Arnold, R. (1999). Increasing organ donation in the African American community. *Annals of Internal Medicine, **130**, 607-9.*

Sloan, R.P.; Bagiella E.; and Powell T. (1999) Religion, spirituality and medicine. *Lancet, **353**, 664-667.*

Sloan, R.P.; Bagiella, E.; VandeCreek, L.; Hover, M.; Casalone, C.; Hirsch, T.J.; Hasan, Y.; Kreger, R.; and Poulos, P. (2000) Should physicians prescribe religious activities? *The New England Journal of Medicine, **342**, 1913-1916.*

Smaje, C. (1995) *Health, race, and ethnicity: making sense of the evidence*. King's Fund Institute, London.

Smith, P.W. (2002). The effects of prayer: scientific study. *Archives of Internal Medicine, **162**, 1420.*

Stern, P.N. (1980) Grounded theory methodology: its uses and process. *Image, **12**, 20-23.*

Stern, P.N. (1994). Eroding grounded theory. In: Morse, J.M.(ed). *Critical issues in qualitative research methods*. SAGE publications, Newbury Park, California.

Strauss, A. (1987). *Qualitative analysis for social scientists*. University of Cambridge Press, New York.

Strauss, A. and Corbin, J. (1990). *Basic of qualitative research: grounded theory, procedures and techniques.* SAGE Publications, Newbury Park, California.

Strauss, A. and Corbin, J. (1998). *Basic of qualitative research (2nd ed).* SAGE Publication, Thousand Oaks, California.

Strawbridge, W.J. (1997). Frequent attendance at religious services and mortality over 28 years. *American Journal of Public Health, **87**, 957-61.*

Strawbridge, W.J.; Shema, S.J.; Cohen, R.D.; and Kaplan; G.A. (2001). Religious attendance increases survival by improving and maintaining good health behaviours, mental health and social relationships. *Annual Behaviour Medicine, **23**, 68-74.*

Stuart, O.P. (1977). *Attitudes and opinions*. Prentice-Hall, New Jersy.

Syed, J. (1998) Islamic views on organ donation. *Journal of Transplant Coordination, 8, 157-160.*

Taliaferro, C. (1998*). Contemporary philosophy of religion*. Blackwell publishers Ltd, Oxford.

Taylor, S. and Bogdan, R. (1998). *Introduction to qualitative research methods: a guidebook and resource (3rd ed)*. John Wiley and Sons, New York.

Terasaki, P.I.; Cecka, J.M.; Gjertson, D.W.; and Takemoto, S. (1995). High survival rates of kidney transplants from spousal and living unrelated donors. *New England Journal of Medicine, 333, 33-36.*

Toronyi, E.; lfoldy, F.; Jaray, J.; Remport, A.; Mathe, Z.S.; Szabo, J.; Gati, Z.; and Perner, F. (1998). Attitudes of donors towards organ transplantation in living related kidney transplantation. *Transplantation International, 11, S481-S483.*

Thomas, G.; Ryall, M.; and Taber, S.M. (1992). Ethical dilemmas in transplantation. *Transplantation Proceedings, 24, 2099.*

Thrower, J. (1999). *Religion the classical theories*. Edinburgh university press, Edinburgh.

Thornett, A.M. (2002). Effect of retroactive intercessory prayer: cautions approach is needed. *British Medical Journal, 324, 1037.*

Toledo-Pereyra, H. (1992) The problem of organ donation in minorities: some facts and incomplete answers. *Transplantation Proceedings, 24, 2162-64.*

Treska, V. and Hasman, D. (2001). Ethical problems with non-heart beating donors. *Rozhledy V Chirurgii, 80, 54–6.*

Twisselmann, B.H. (2002). Is religion good for your health? *British Medical Journal, 324, 1044.*

UK Transplant (2001). *Yearly transplant statistics*. Audit report. Bulletin. Bristol.

UK Transplant (2003). http://www.uktransplant.org.uk

Van Der Vliet, J.A.; Cohen, B.; Vroemen, J.P.; Ruers, T.J.; and Kootstra, G. (1984) Successful reorganisation of organ procurement in the Netherlands. *Transplantation Proceedings, 16, 191.*

Voiculescu, A.; Ivens, K.; Hetzel, G.R.; Hollenbeck, M.; Sandmann, W.; Grabitz, K.; Balzer, K.; Schneider, F.; and Grabensee, B. (2003). Kidney transplantation from related

and unrelated living donors in a single German centre. *Nephrology, Dialysis, and Transplantation, 18, 418-25.*

Wakeford, R.E. and Stepney, R. (1989). Obstacles to organ donation. *British Journal of Surgery, 76, 435-439.*

Wallace, J.M. and Forman, T.A. (1998). Religion's role in promoting health and reducing risk among American youth. *Health Education Behaviors, 25, 721-41.*

Wallis, C. (1996) Faith and healing. *Time, 24, 58-63.*

Walsh, A. (1998) Religion and hypertension: testing alternative explanations among immigrants. *Behaviour Medicine, 24, 122-130.*

World Health Organisation (WHO) (1998). *Exective Board meeting Document* 101, Geneva.

Yankelovich, P. (1996). Telephone poll regard religious believe. *Time, 58-62.*

Yin, R.K. (1989). *Case study research: design and method.* SAGE Publications, London.

Yin, R.K. (1994). *Case study research: design and methods (2nd ed)*. SAGE Publication, California.

Yuen, C.C.; Burton, W.; Chiraseveenu, P.; Elmore, E.; Wong, S.; Ozuah, P.; and Mulvihill, M. (1998). Attitudes and beliefs about organ donation among different racial groups. *Journal of The National Medical Association, 90, 13-18.*

Appendix 1

Statement of the Islamic Organisation for Medical Sciences about the Medical Definition of Death.

Symposium held in Kuwait, 17-19 December 1996

In 1985, the Islamic Organisation for Medical Sciences held a symposium to study "The End of Human Life", participating in which were a select group of top religious jurists, medical scholars, legal experts and authorities in the humanities. After meticulous discussion, the symposium endorsed the following conclusion:

1- In the great majority of cases, when death happens, there is no difficulty in its diagnosis, based on self-evident widely recogmised features or an external clinical examination distinguishing the dead from the living.

2- In some (very few) cases, usually under close observation in the intensive care units or similar specialised hospital wings, the need is intense to establish the diagnosis of death, even at the phase when life-like phenomena persist, either spontaneously or by means of artificial life support machinery.

3- The time honored books of jurisprudence were scrutinised in to determine view on the signs that prove death. These were mainly human interpretations based on available medical knowledge at their time, in view of the absence in the *Qur'an* and the traditions of the Prophet of a clear-cut definition of death. Since the diagnosis of death and its signs have always been in the medical domain, upon which the jurists based their rulings, the medical side presented to the symposium current medical opinion on the definition of death.

4- After the medical scholars presented their case, the following points became clear:

- the death of that part of the brain responsible for the primary vital functions, which is called the brain stem, is a reliable indicator of the occurrence of death.

- that the diagnosis of brain stem death is based on clear cut and reliable evidence, having excluded well known clinical entities that might give a false positive diagnosis.

- a vital organ or function like the heart or respiration might stop temporarily but can sometimes be saved with restoration of life: but only if the brain stem is alive. If the brain stem has died, there is no prospect of such rescue, and the person's life has practically come to a conclusion, even if other organs or systems have not died yet they inevitably also die after a period of time.

5- Upon these medical data, the religious jurists based the view that if a person has reached, with certainty, the state of brain stem death, then such a person has departed from his life, and some of the rulings concerning death are applicable to him. This is analogous- although not identical- to the juridical ruling about the person that reached the stage of "movement of the slain". Concerning the applicability of the other rulings, the jurists preferred to defer discussing them for a future occasion.

6- In the view of all this, there was a consensus that if death of the brain stem is diagnosed with certainty, then disconnecting the person from artificial life support apparatus may be carried out.

The Islamic Organisation for Medical Sciences, keen on pursuing any scientific developments on the matter, and feeling the duty to address a recent campaign in the lay

press and public media discrediting the standard universal acceptance of brain death with brain stem death as diagnostic of death, decided to hold this symposium. Some doctors participated to that campaign, which added to the urgency of the situation. Two decisions were taken:

(i) The Organisation deputed three of its members to participate in the November 1996 international conference held in San Francisco, U.S.A, by the American Association of Bio-ethics, the International Association of Bio-ethics and the network to study the Definition of Death. They reported that there was no departure from the standing definition of death by brain death together with brain stem death. No patient where brain and brain stem death was correctly diagnosed ever came back to life, and none of the people who that came back to life carried an established diagnosis of brain and brain stem death.

(ii) A distinguished group of scholars in the specialities of neurology, neurosurgery, anaesthesiology, intensive care, neurophysiology, cardiac surgery, organ transplantation, medicine, paediatrics, obstetrics and gynaecology, general surgery, medical jurisprudence; who came from Kuwait, Saudi Arabia, Egypt, Lebanon, Turkey and United State of America, was invited to the symposium in Kuwait from 17-19 December 1996. It was also attended by the Director of the East Mediterranean Regional Office EMRO) of the World Health Organisation.

The subject was comprehensively discussed over tree days, including a meticulous appraisal of the clinical cases presented in support of the dissent- no person properly diagnosed as brain and brain stem death ever regained life, and all the people that regained life had an obvious and flagrant fault in making such diagnosis, omitting, misreading or violating the standard criteria.

Reviewing the global situation and the regional experiences and safeguards taken (the contribution of the Saudi team was particularly commendable) and in full awareness of the scientific and religious dimensions, the Organisation found no reason to discard,

modify or alter the recommendation of its previous symposium on "Human Life: Its beginning and its end" held in Kuwait in 1985, or the rulings issued by the Congress of Islamic Jurisprudence (a department of the Organisation of Islamic Congresses) in Makkah in 1986, both of which have been reaffirmed.

The following standards, criteria and safeguards were spelt out by the Symposium, and the Organisation herewith presents them for the benefit of formulating legislation and by-laws regulating this subject.

First, signs which signify death:

An individual is considered dead in one of the following two situations:

a- Complete irreversible cessation of respiratory and cardiovascular systems.
b- Complete irreversible cessation of the functions of the brain including the brain stem

This should be confirmed using the accepted medical standards.

Second, guidelines for diagnosing brain and brain stem death:

a- The presence of a reliable medical specialist well experienced in the clinical diagnosis of brain and brain stem death and the various implications of such a diagnosis.
b- Prescribed observation necessitates complete medical coverage in a specialised suitably equipped institution.
c- Second opinion should be accessible whenever sought.

Preconditions necessary before considering the diagnosis of brain death:

1- The person must be in continuous deep uninterrupted coma.
2- The cause of the coma can be explained by extensive damage to the structure of the brain, such as severe traumatic concussion, massive intracranial hemorrhage,

after intracranial tumor or obstructed blood supply to the brain: confirmed by adequate diagnostic measures.

3- At least six hours have passed since the onset of coma.
4- There is absence of an attempt at spontaneous breathing.

The diagnosis of complete irreversible cessation of brain and brain stem function necessitates:

1- Deep coma with complete unreceptiveness and unresponsivity.
2- The clinical signs of absence of brain stem functions including absence of the pupillo-corneal reflex, absence of oculo-cephalic reflex, absence of oculo-vestibular reflex, absence of the gag reflex and absence of the cough and vomiting reflexes.
3- Absence of spontaneous breathing as confirmed by the apnea test when the respirator is temporarily disconnected.

It should be borne in mind that:

- Some spinal reflexes may persist for some time after death. This is not incompatible with the diagnosis of brain death.
- Conclusions ensuing upon "decortication" or "decerebration", and also "epileptic seizures", are incompatible with the diagnosis of brain death.

All cases should be excluded which may be reversible or curable such as:

If the patient is under the influence of sedatives, tranquilizers, narcotics, poisons or muscle relaxants; or if he/she has hypothermia below 33C; or in an untreated cardiovascular shock, metabolic or endocrine disturbances that might lead to coma.

There should be certainty of complete cessation of brain function over a period of observation of:

12 hours since the onset of irreversible coma.

24 hours if the coma is due to cessation of circulation (such as cases of cardiac arrest).

In children under 2 months of age, the observation period is extended to 72 hours, followed by repetition of electroencephalography or tests for cerebral circulation.

Children between 2 and 24 months of age require a longer observation period of 24 hours followed by repeat encephalography.

Children over one year of age are handled like adults.

Specifications of the team authorised to diagnose brain death:
The team comprises two specialists with experience in diagnosing brain death. A neurologist's opinion is also sought if necessary.

One of the two doctors of the team should be a specialist in neurology, neurosurgery or intensive care.
No member of the team should be
A member of the organ transplantation team,
A member of the family of the deceased person,
Have any special interest in the declaration of death (such as inheritance or bequest)
Blemished by any accusation by the family of the deceased that he had committed any professional misconduct.

With all this, the Islamic Organization for Medical Sciences, with an immense sense of duty towards the Islamic Shariah and the public welfare which the Shariah aims at, appeals to all concerned to confine the discussion of such a sensitive issue within the relevant medical and scientific circles, instead of taking it out in a sensational way to the lay media shattering the confidence and trust of the public that was not given the complete/ correct data.

It would also behove the relevant authorities in Muslim countries to issue legislation defining, regulating and safeguarding the diagnosis of death and the practice of organ

donation and transplantation based upon the Islamic Shariah, for a legal vacuum is only conducive to confusion or malpractice.

The creation of a venue enabling the organ transplantation centres in Arabic and Islamic countries to communicate, network and exchange views and experiences, should be given appropriate priority.

Appendix 2

The Muslim Law Council in the UK

On 26 August 1995

Islam holds that Man consists of two essential elements, one material which is the body, the other spiritual which is the soul. Life exists in the human body as long as the soul is joined to it, and it ceases when the soul departs from the body.

> *Who made all things good, which He created, and He began the creation of man from clay then He made his seed from a draught of despised fluid. Then He fashioned him and breathed into him of His Spirit, and He appointed for you hearing and sight and hearts. Yet small thanks do you give for it.* (32:7-9)

Thus the cessation of life means the departure of the soul from the body:

> *Allah recalls souls at the time of their death, and those who have not died, during their sleep. He holds on to anyone whom death has been decided for, and sends the others back for a specific period.* (39:42)

The soul is a mysterious thing and nobody has been able to discover its nature. Its presence in the body results in life which is observed by the movement and the other conventional signs of life. The departure of the soul from the body results in death, which is associated with certain physical signs arrived at as a result of medical observations and knowledge.

The signs of death which the ancient medical doctors have listed are: lack of consciousness, loss of body temperature, cessation of pulse and breathing, glazing of the eyes, parting of the lips, sagging of the nose, and slacking in the muscles of the hands and feet. The heart used to be considered as the centre of life in the body. When it stopped completely it was assumed that death had occurred. But if it regained its functions through first aid practices life is assumed to have returned.

The last five decades have witnessed a big leap in medical science bringing great benefits and skills which were unthinkable before. It is now possible to transplant organs from one body into another, which would help the recipient to continue to live.

The significance of the heart has also changed as it is no longer considered the most important organ with regard to life and death. Medical opinion now considers the brain to be the central and crucial part which controls the entire body and its functions.

When it is damaged partially or totally the body will suffer either partial or total deterioration. As a consequence of the present developments in medical knowledge and skills a number of questions have arisen. There are:

Is it allowed to remove an organ like the kidney from the body of a living person and transplant it into the body of a sick person whose life depends on it? Is it permissible to remove an organ from the body of a dead person to be used to save the life of a living person? Is a person allowed to donate his body or part of it to be used after his death in saving the life of other people? Does Islam recognise the new definition of death that is brain stem death?

If it does, is it permissible to remove from brain stem dead person organs for transplantation while there are signs of body functions like heartbeat, temperature above ambient values, and breathing?

Before answering these questions it is important to note the following principles of Islamic Jurisprudence (*Usul-Fiqh*):

- A person has the legal authority over his own body, attested by the fact that he can hire himself for work which might be difficult or exhausting. He may also volunteer for war which may expose him to death.

- A person is forbidden from harming himself or others (It is not legitimate in Islam to inflict harm on others or to suffer harm from them - *Hadeeth*).

- In case of necessity certain prohibitions are waived as when the life of a person is threatened the prohibition on eating carrion or drinking wine is suspended.

> *He has only forbidden you what has died by itself, blood and pork, and anything that has been consecrated to something besides God. Yet anyone who may be forced to do so, without craving or going too far, will have no offence held against him; for Allah is Forgiving, Merciful.* (2:173)

Confronted with two evils a person is permitted to choose the lesser of the two, as in the case of a starving person whose life could be saved by either eating carrion or stealing from another person's food. He would be permitted to opt for the latter. Islam made it an obligation upon the sick to seek treatment.

In the light of the above principles the Council is of the opinion that:

1. It is permissible for a living person to donate part of the body such as the kidneys to save the life of another, provided that the organ donated would not endanger the donor's life and that it might help the recipient.

The Prophet (s.a.w.) says,

> *Whoever helps a brother in difficulty, God will help him through his difficulties on the Day of Judgement.*

2. It is permissible to remove the organ of a dead person to be used to save the life of a sick person.

3. It is permissible for a person to donate his body or parts of it to be used after death to treat those who need transplants. So it is permissible for Muslims to carry a donor card.

4. In the absence of a donor card carried by the dead person it is sufficient to obtain the consent of the next of kin.

5. The proper authorities will act *in lieu of* relations if they are not known.

Regarding brain stem death, the Council, having discussed the matter over a number of meetings with Doctors and specialists, and having studied the safeguards instituted by the Ministry of Health in Great Britain, went further and examined the research done by trustworthy Muslim Doctors and noted the following:

- If the heart stops beating then lack of consciousness and the cessation of breathing will follow immediately.

- If however the person is helped by massage of the heart (CPR) or through the use of electric shock (defibrillation) within four or five minutes the heart may restart.

- If the flow of the blood to the brain ceased for more than a few seconds damage may occur, although some of the cells will remain alive for four or five minutes. On the other hand if the brain stem ceases to function it cannot be made to restart.

- After the brain stem is dead it is possible to preserve some organs functioning for a period from six hours to two weeks. The presence of pulse or movement after the death of the brain stem is not a sign of life. We know that a hanged or beheaded person

continues to have pulse and movement for a brief period. But they are not considered to be alive and it would not be possible to bring them back to life.

Based on the above the medical profession concludes that life ceases as a result of brain stem death.

The Council is of the opinion that trustworthy Doctors are the proper and authentic authority when it comes to defining the signs of death.

After a thorough consideration regarding medical opinion and several edicts issued by different religious bodies, the Council arrived at the following conclusions:

After trustworthy Doctors certify that the brain stem has died organs needed to save others' lives might be taken from the body, and then the life support machine may be switched off.

While the Council recognises the need for benefiting from the advances of medical science in alleviating the suffering of the sick and saving lives, it wishes to remind everyone especially Doctors of the following points:

Human beings are the most honoured creatures on earth. Their dignity in life and death must be maintained.

> *We have dignified the Children of Adam and transported them around on land and at sea. We have provided them with wholesome things and favoured them especially over many of those whom We have created.* (17:70)

Human life is sacred. To terminate the life of one person is equivalent to the termination of the life of all humanity. Conversely the saving of one life is regarded as the saving of all humanity.

> *Whosoever kills any person without another soul being involved or for causing corruption in the earth, it shall be as if he had*

killed all mankind and whosoever saves the life of one it shall be as if he had saved the life of all mankind. (5:32)

The Council is of the opinion that human organs should be donated, and not sold. It is prohibited to receive a price for an organ.

List of the Ulama' and Scholars who participated during the consultation and then approved the statement on Organ Transplant:

1. Dr M A Zaki Badawi, Principal, The Muslim College, London and Chairman, The Muslim Law (Shariah) Council UK.
2. Dr Jamal Sulayman, Professor of Shari'ah, The Muslim College, London.
3. Dr A A Hamid, Professor of Hadeeth, The Muslim College, London.
4. Dr Fazel Milani, Professor at The International College of Islamic Sciences London.
5. Dr S M A Shahristani, Principal, The International College of Islamic Sciences London.
6. Moulana Abdul Hadi Umri, General Secretary, Jamia-te-Ahl-e-Hadith (UK).
7. Moulana Qamaruzzaman Azami, Chief Imam, North Manchester Central Mosque & General Secretary, The World Islamic Mission.
8. Mufti Mohammed Yunus, President, The World Islamic Mission & Imam, Woking Mosque.
9. Mufti Mohammed Muniruzzaman, Imam, Munir-ul-Islam Mosque, Rochdale.
10. Dr Abdul Halim, Senior Imam, The Islamic Cultural Centre and London Central Mosque, Regent's Park London.
11. Mufti Alauddin, Head Imam, Brick Lane Central Mosque, London.
12. Moulana Hafiz M Khalid, Head Imam, Sparkbrook Islamic Centre, Birmingham.
13. Moulana Mumtaz Ahmed, Imam of Bradford.
14. A A Bashiri Esq. Barrister-at-Law.

15.R Abdullah Esq. Barrister-at-Law.

16.Dr Safia Safwat, Barrister-at-Law.

17.Moulana M Shahid Raza, Director, Islamic Centre Leicester & Secretary, The Muslim Law (Shariah) Council UK.

18.Mr S G Syedain, General Secretary, Imams & Mosques Council, UK.

19.Dr. Manazir Ahsan, Director of the Islamic Foundation.

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