

**A grounded theory study of the issues and
challenges that impact on transplant
coordinators and their practice**

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In loving memory of my father

James Kelly

Who shared my life for 10 years & 10 months

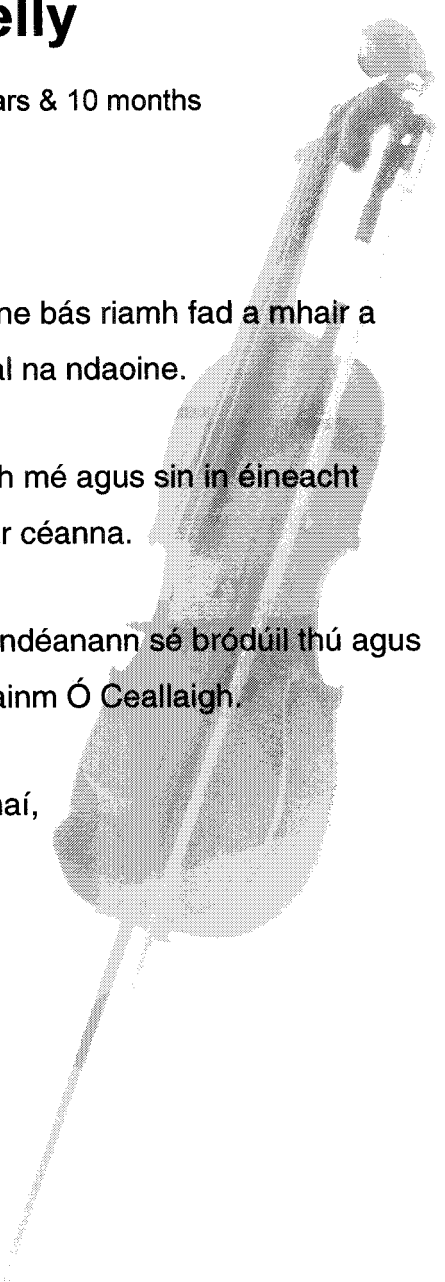
Chreid na Gaeil fadó nach bhfuair daoine bás riamh fad a mhair a
n-ainmneacha beo i mbéal na ndaoine.

Sa chomhthéacs sin níor fhág tú riamh mé agus sin in éineacht
a chéile ar an mbóthar céanna.

Is duitse an tráchtas seo; tá súil agam go ndéanann sé bródúil thú agus
go mbronann sé onóir ar an ainm Ó Ceallaigh.

Mo ghrá i gcónaí,

Máire.



J. Kelly

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—oOo—

In the beginning . . .

Elizabeth Yeo
First Australian Organ Donor Coordinator



Michael McBride
First Australian Recipient Coordinator



Carol Whitfield
First New Zealand Recipient Coordinator



Joanna Innes Walker
First New Zealand Organ Donor Coordinator



Acknowledgement of the transplant coordinator pioneers in Australia and New Zealand

I would like to take this opportunity to acknowledge and thank the
first donor and recipient transplant coordinators

in

Australia and New Zealand.

They were true pioneers who forged a tradition in our countries of
teamwork, commitment and dedication to organ and tissue donors,
donor families, organ and tissue recipients, recipient families, carers
and of course their colleagues.

Over the course of this thesis I have had the privilege of speaking
with three of these coordinators and meeting two of the late
Elizabeth Yeo's children.

I am humbled by the remarkable work they did and am honoured to
have been a donor coordinator and now a recipient coordinator.

To these transplant coordinator pioneers and all those who have been
or continue to be transplant coordinators - I would like to acknowledge
and thank you all for the positive contributions you have made and
continue to make to donor families, recipients and our unique
discipline.

Mary J Kelly
Transplant Coordinator

Presentation and awards – prior to 2008

The findings of this study were first presented by

Mary J Kelly

PhD Candidate - The University of Adelaide

at the

Australasian Transplant Coordinators' Association and Transplant Nurses'
Association Annual Conference, '**Pushing the Boundaries**',
Rendezvous Hotel, Melbourne, 15th – 17th November 2007.

This presentation was awarded the following:

BEST CONFERENCE PAPER

&

The 2007 ATCA 'ELIZABETH YEO' Award

Declaration

I declare that the content of this thesis has not been submitted for any degree and is not currently being submitted for any other degree or qualification.

I also declare that any assistance received in preparing this thesis and all sources used have been acknowledged in the thesis.

I give consent to this copy of my thesis, when deposited in the university library, being available for loan and photocopying.

.....
.....
Mary Johanna Kelly
September 2007

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List of Abbreviations

ABTC	American Board of Transplant Coordinators
ADAPT	Australasian Donor Awareness Programme for Transplantation
ACCCN	Australian College of Critical Care Nurses
AOPO	Association of Organ Procurement Organisations
ATCA	Australasian Transplant Coordinators' Association
DCD	Donation after Cardiac Death
ETCO	European Transplant Coordinators' Organisation
ICE	Institute of Continuing Education – Australian College of Critical Care Nurses
ICU	Intensive Care Unit
ISHLT	International Society of Heart and Lung Transplantation
ITCS	International Transplant Coordinators' Society
NATCO	North American Transplant Coordinators' Organization
NHBD	Non Heart Beating Donors
NOMS	National Organ Matching System
OPO	Organ Procurement Organisation
ORS	Organ Recovery Systems Inc.
QWL	Quality of Work Life
SAODA	South Australian Organ Donation Agency
SATODAC	South Australian Transplantation and Organ Donation Advisory Council
TGA	Therapeutic Goods Association
TNA	Transplant Nurses' Association
TOPF	Transplant Organ Procurement Foundation
TSANZ	Transplant Society of Australia and New Zealand
UNOS	United Network for Organ Sharing

Glossary of Transplant Coordination Terms

Australasian Transplant Coordinators' Association (ATCA)

ATCA is a professional association for transplant coordinators. It was first established in 1988 and became an incorporated body in 1990. The aims of ATCA are to foster communication and collaboration between transplant coordinators and to promote education and the ongoing advancement of organ donation and transplantation. ATCA also provides a forum to discuss transplant coordination issues, implement changes and represent the interests of its members (Armstrong 1994).

Australians Donate Incorporated

Australians Donate is the peak body for organ donation in Australia. It is a non-profit government funded national organisation that works to improve organ and tissue donation awareness and donation rates within the Australian community. Australians Donate works in collaboration with other organisations that are involved in the field. These include key stakeholders such as organ donation agencies, tissue and eye banks, transplantation units, academics, policy makers and ethicists (Coleman 2003).

Brain death

Brain death is the irreversible cessation of brain function characterised by the absence of blood flow to the brain. It is determined by clinical assessment or a cerebral perfusion scan. A person in whom brain death is confirmed is dead although their cardiopulmonary functioning may be artificially maintained for a self-limiting period of time (UNOS 2005).

Cadaveric donation

Cadaveric donation occurs when organs and/or tissues are taken from a cadaver (i.e. a dead person) for the purpose of transplantation and/or research.

Donor coordinator

A donor coordinator is a person who organises the organ donation process. This includes the consenting procedure, organising serology testing and tissue typing, legal aspects of donation, distribution of organs, assisting in theatre, the shipment of organs and care of the donor family.

Donor family

The donor family are significant others or relatives of the donor. Therefore the donor family may involve a friend, defacto, or anyone who identifies as a significant other to the deceased.

Live donation

Live donation refers to a person who donates an organ such as a kidney, or a part of an organ, for example a segment of their liver, when they are alive to another human being to either save or improve that person's quality of life.

Marginal organs

As the term suggests these are organs that may or may not be suitable for transplantation. They are still offered to transplant units. There may be a critically ill potential recipient on the waiting list who may be given the option of accepting a 'less than perfect organ' because they are in grave danger of dying if they do not receive a transplant almost immediately.

Medically unsuitable organs

These are organs that are not suitable for transplantation for medical reasons such as trauma to the organ, insitu cancer, and deterioration during the patients' hospital admission or after declaration of brain death. Organs can be deemed not medically suitable for transplantation prior to them being offered to transplant units or conversely the transplant unit staff may deem them medically unsuitable.

Non-heart beating donor or donation after cardiac death

This refers to the retrieval of cadaveric solid organs and/or tissues from donors who have died following cardiac arrest. Unlike brain dead patients these patients have no beating heart and therefore no intact circulation when organs are retrieved. Donation therefore commences following cardiac arrest/standstill.

Organ allocation

Organ allocation refers to the distribution of organs to potential recipients. Organ allocation is a process, which takes into account the guidelines, policies and ethical considerations that need to be addressed to ensure the equitable distribution of this scarce resource (UNOS 2005).

Organ Recovery Systems Inc.

Organ Recovery Systems, Inc. (ORS) is a non-profit corporation in Texas (USA) that manages organ procurement organisations. ORS provides various administrative services including financial, legal, accounting, data processing, human resources and purchasing for the organ procurement organisations (OPOs) (Haid, House, Kea, Hott, Wagner & Whisennand 1993).

Organ donation agency

An organ donation agency is a non-profit organisation that is responsible for the promotion of organ donation and the facilitation of the organ donation process. Organ donation agencies are also responsible for donor family care both in the short and longer term.

Organ donation process

This refers to the process from the time of donor referral from the Intensive Care Unit to the time that organs are shipped safely to their respective destinations. This process is complex and time-consuming. It includes – a discussion(s) with the donor family regarding organ donation, the consenting process from the donor family, designated officer (medical person in charge of the hospital) and the coroner, gathering medical data, donor measurements, organising appropriate blood tests, organ allocation, organ retrieval and perfusion, the shipment of organs and follow-up care of the donor family including a viewing of the deceased if requested.

Organ donation and transplantation process

This involves the total organ donation and transplantation process from donor identification and notification, retrieval and shipment of organs to the transplantation of the donated organs into the recipients. It also includes the follow-up care of the donor family, recipient and recipient families.

Organ donor

An organ donor is a person who donates one or more of their solid organs or tissues to another human being for the purpose of either saving or improving the recipients' quality of life. In the context of this research, organ donor refers to those that donate following death and does not include live donation.

Organ procurement organisations (OPOs)

This is the name given to organ donation agencies in the USA. Like Australian and New Zealand agencies, these organisations are also responsible for the promotion of organ donation and the facilitation of the organ donation process. They are also responsible for donor family care at its many levels. In the USA these facilities are required to reach minimum organ donation quotas to be assured of ongoing funding. As within Australia and New Zealand, they are non-profit organisations.

Perfusion

This refers to the process of perfusing organs in theatre during the organ donation and transplantation process.

Perfusionists

The perfusionist is a person who perfuses or flushes the organs with one or more of the following perfusion fluids – for example University of Wisconsin (UW), pneumoplegia or cardioplegia. Perfusion commences once cross-clamping has occurred in heart-beating donors or in the case of non-heart beating donors once aortic access has been established.

Recipient

A recipient is a person who receives solid organs or tissues from another human being in order to save or improve their quality of life. The recipient may receive these organs or tissues from a live donor or a cadaveric donor. In the context of this research, recipient refers to those who receive cadaveric solid organs.

Recipient coordinator

The recipient coordinator is a person who organises the transplantation process. This includes locating and informing the potential recipient that an organ has become available for transplantation, cross-matching, the legal aspects of transplantation and organisation of transport for the retrieval team(s), the organs and/or recipients in conjunction with the organ donor coordinator. They are also responsible for recipient care pre- and post-transplantation in the short and longer term.

Retrieval

Retrieval is the term used to denote the surgical removal of solid organs or tissues from a donor's body. Another term used to describe this practice is harvest. Out of respect for donors and their families the medical, nursing and organ donation and transplantation fraternities are encouraged to use the term retrieval. Other terms used through out the world include procurement and organ recovery.

Retrieval teams

Retrieval teams are the medical, nursing and coordination staff who are involved in the process of organ/tissue retrievals. In this study the retrieval teams refer to the health personnel who are involved in the surgical removal of solid organs from cadaveric donors.

Rotation Lists

These are the lists that organ donor coordinators use to distribute solid organs – such as hearts, lungs and livers to transplant units through out Australia and New Zealand. This occurs providing that the transplant unit in their own state declines the offer or if there is no surgical unit for that particular organ. These organs are offered on a rotational basis.

Kidney allocation is controlled by a central system known as the National Organ Matching System (NOMS).

Solid organs

These are the internal organs that can be donated for transplantation and include heart, lungs, liver, pancreas and kidneys. Usually these organs can only be retrieved from brain dead patients. In certain circumstances some of these solid organs can be retrieved from live donors or non-heart-beating donors - now referred to as donation after cardiac death.

Tissues

This includes eyes that are removed from cadaveric organ donors to retrieve the corneal tissue for transplantation, heart valves, bone and skin. All tissue is used to improve a recipient's quality of life. Tissue can be retrieved from brain dead patients and from those who have had a cardiac death.

Tissue coordinator

The tissue coordinator is a person who organises the retrieval, storage and transplantation of donated tissues. Tissue coordinators are not included in this study.

Tissue typing

Tissue typing is the blood test that is used to evaluate how closely the tissues of the donor are to those of the potential recipients (UNOS 2005).

Transplant coordinator

The transplant coordinator is a person who organises the organ donation and transplantation process. If the transplant coordinator is employed in the organ donation field they are responsible for organising the organ donation process. If they are employed in the area of transplantation they are responsible for organising the transplantation process. Transplant coordinator is the collective name given to organ donor coordinators, donor coordinators, recipient coordinators, clinical coordinators or procurement coordinators in this study.

Transplant Nurses' Association (TNA)

TNA is a professional association for transplant nurses. It was formed in 1990 and has since become incorporated in New South Wales. The aims of the TNA are to advance the education of nurses and allied health professionals involved in transplantation. The TNA also works to develop a network between members for the exchange of information and to provide transplant nurses with standards of care, which will foster best practice in their field (Transplant Nurses' Association 2002).

Transplantation process

This is the process from the time of the initial referral from the organ donor coordinator to the recipient coordinator, to the transplantation of the organ or organs into the selected recipient or recipients. It takes a considerable amount of time and coordination to successfully complete this process.

Abstract

The purpose of this study is to identify and explore issues and challenges that impact on transplant coordinators and their practice. Such identification enhances understanding of their role, provides evidence for decision-makers to facilitate the positive aspects of the coordinators' practice, highlights their professional needs and contributions and provides baseline data for future research, education and policy development.

The study used both qualitative and quantitative data. Data collection methods involved focus group interviews and Delphi surveys. Participants were coordinators who were employed on a full-time, part-time or relieving basis. Recruitment of participants was done by purposive and snowball sampling. There were 112 coordinators in the study and each was randomly assigned to the focus groups or Delphi survey phases of the research. The analysis of the focus group data together with the literature, informed the development of the first Delphi survey. The second Delphi survey was developed using the data from the focus groups, literature and the first survey.

Four categories emerged from the data. The first involved 'knowledge and experience', which explored the education needs of coordinators and the issue of nursing qualification requirements. The work environment, demands and conditions, together with role attributes were discussed in the next category – 'the role'. Recipient, donor family and transplant coordinator outcomes were addressed in the 'outcomes' category. The basic social process – building relationships – explored the relationships that coordinators have with the health team and their client groups. Four types of relationships emerged which were supportive, non-supportive, aggressive and virtual relationships.

The emergent theory of the challenges that transplant coordinators face relates to the building of relationships. The theory also discovers how knowledge and experience, the role and outcomes impact on the building of these relationships in an interdependent manner. This study also emphasises that the transplant coordinators' role is complex, demanding and distinctly unique in terms of the context within which coordinators practice.