UTS UNIVERSITY OF TECHNOLOGY SYDNEY

COMmunication with Families regarding ORgan and Tissue Donation after Death in Intensive Care.

by Julie Elizabeth Potter

Thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

under the supervision of Prof Lin Perry, Dr Rosalind Elliott and Assoc Prof Michelle Kelly

University of Technology Sydney
Faculty of Health

January 2021

Certificate of Original Authorship

I, Julie Potter declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the School of Nursing and Midwifery/Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise reference or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

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Statement Indicating the Format of the Thesis

This thesis is formatted by compilation. It is formatted as a single manuscript that is compiled from published and publishable papers distributed through the thesis and presented in chapters.

Structure of the Thesis

This thesis is presented in eight chapters. Six chapters are a compilation of unpublished and published material. Of those, chapters 2 and 3 are presented in the form of peer reviewed journal articles (submitted and published, respectively). To meet journal requirements for manuscript submission, spelling includes British English (Chapter 2). References are included at the end of the thesis.

Chapter 1 presents contextual background information underpinning the research questions for this thesis and explains the significance of the work. This chapter contains material from the background section of the study protocol published in the journal *BMC Health Services Research* in 2017 (see Appendix 1).

Chapter 2 presents a systematically conducted integrative literature review of specialised communication skills training for critical care HCPs who deliver news of death or discuss withdrawal of life-sustaining treatments, and/or offer organ donation. Outcomes examined include changes to HCPs' communication skills and the effect on family consent rates for deceased organ donation. The search strategy and a typology of communication behaviours are provided in Appendix 2. This paper was submitted to the journal *Patient Education and Counseling* in July 2020 and accepted for publication on 16 March 2021.

Chapter 3 of this thesis is the accepted manuscript published in the journal *Progress in Transplantation* in 2017 (see Appendix 3). It described an innovative program using high-fidelity simulation for selected critical care healthcare professional (HCP) "designated requesters" to rehearse the family donation conversation. Published material contains the development and preliminary evaluation of the study intervention from the experiences and perspectives of HCP participants.

Chapter 4 sets out the study research methods with content expanded on the much briefer version published in the study protocol in the journal *BMC Health Services Research* in 2017 (see Appendix 1). Details have been supplemented by material published in the methods section of the paper reporting results of the primary cohort, published in the journal *Critical Care and Resuscitation* in 2018 (see Appendix

4). In this thesis, the term ‘primary cohort’ used in this paper will be referred to as the ‘unregistered subsample’: donor-eligible patients who had not previously registered their donation preferences on their NSW driver licence and/or the Australian Organ Donor Register, or who were aged 16 years or less.

Chapter 5 presents results for research questions one to three. It begins by describing the clinical settings, including staffing levels in the study ICUs and daily routines. For research questions one and three, reporting of the primary end point of the study is based on content of the publication in which these findings were reported. This paper was published in the journal *Critical Care and Resuscitation* in 2018 (see Appendix 4). For research question two, the care process secondary end points of the study, unpublished findings are presented.

Chapter 6 presents results for research questions four and five. It begins with the findings for research question four, describing the next of kin decision-makers’ reasons for their final organ donation decision at the hospital. Research question five describes abbreviated findings in relation to eligible next of kin follow up interviews at around 90 days after enrolment. It reports whether they regretted their final donation decision, either to consent or to decline donation.

Chapter 7 sets out the discussion of the main findings of the study according to the research questions. This chapter includes published material from the discussion section of the study protocol published in the journal *BMC Health Services Research* in 2017 (see Appendix 1). Regarding research question 1, this chapter contains material from the discussion section of the paper reporting results of the primary cohort, published in the journal *Critical Care and Resuscitation* in 2018 (see Appendix 4). The overall implications of the findings are situated within the Australian and international literature. This chapter concludes by describing the strengths and limitations of the project.

Chapter 8 discusses the implications of the project for practice, policy and future research, and concludes the thesis.

The appendices to this thesis include copies of lead Human Research Ethics Committee approvals, with ratification by the UTS Human Research Ethics Committee, participant information sheet and consent forms, case report forms (CRF), copies of publications, and copyright permissions.

Publications Included in the Thesis

Paper #1	
Title:	COMmunication with Families regarding ORgan and Tissue donation after death in intensive care (COMFORT): protocol for an intervention study.
Authors:	**Potter J,** Herkes R, Perry L, Elliott R, Aneman A, Brieva J, Cavazzoni E, Cheng A, O'Leary M, Seppelt I, and the COMFORT study investigators.
Journal:	*BMC Health Services Research* 2017;(1):42. doi: 10.1186/s12913-016-1964-7
Status of publication:	Published 17 Jan 2017.
Unique contribution to knowledge	This article describes the study protocol for the implementation and evaluation of a best practice family approach intervention for "designated requesters" leading the family donation conversation in the clinical setting of an intensive care unit. Material from this article appears in the thesis introduction Chapter 1, and in the methods Chapter 4.
Paper # 2	
Title:	Simulation-based communication skills training for experienced clinicians to improve family conversations about organ and tissue donation.
Authors:	**Potter JE**, Gatward JJ, Kelly MA, McKay L, McCann E, Elliott RM, Perry L.
Journal:	*Progress in Transplantation* 2017;27(4):339-345. doi: 10.1177/1526924817731881
Status of publication:	Published online 9 Nov 2017.
Unique contribution to knowledge	This article describes an innovative program using high-fidelity simulation for selected critical care healthcare professional 'designated requesters' to rehearse the family donation conversation. Material includes evaluation of the study intervention from the experiences and perspectives of participants. This article appears in the thesis development and evaluation of the intervention Chapter 3.
Paper # 3	
Title:	COMmunication with Families regarding ORgan and Tissue donation after death in intensive care (COMFORT) intervention: a multicentre pre-post study.
Authors:	**Potter J**, Perry L, Elliott R, O'Leary M, Aneman A, Brieva J, Cavazzoni, E, Cheng A, Seppelt I, Herkes R and the COMFORT investigators.

Journal:	*Critical Care and Resuscitation* 2018;20(4):268-276
Status of publication:	Published 3 Dec 2018.
Unique contribution to knowledge	This article describes the effect of the study intervention on family consent rates for deceased organ donation in cases where the donor-eligible patient had not recorded their donation preference on a donation register or their driver licence. Material from this article appears in the thesis methods Chapter 4, primary end point results in Chapter 5, and the discussion Chapter 7.
Paper # 4	
Title:	Education and training methods for healthcare professionals to lead conversations concerning deceased organ donation: an integrative review.
Authors:	Potter JE, Elliott RM, Kelly MA, Perry L.
Journal:	*Patient Education and Counseling*
Status of publication:	Submitted 23 July 2020. Accepted for publication on 16 March 2021.
Unique contribution to knowledge	Systemically conducted integrative review on specialised communication skills training for critical care healthcare professionals who deliver news of death or discuss withdrawal of life-sustaining treatments, and/or offer organ donation in critical care settings. This article appears in the thesis literature review Chapter 2.

Journal permissions to reproduce the articles in the thesis are located in Appendix 14.

Statement of Contribution of Authors

Paper 1 COMmunication with Families regarding ORgan and Tissue donation after death in intensive care (COMFORT): protocol for an intervention study. *BMC Health Services Research* 2017;(1):42. doi: 10.1186/s12913-016-1964-7.

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Paper 2 Simulation-based communication skills training for experienced clinicians to improve family conversations about organ and tissue donation. *Progress in Transplantation* 2017;27(4):339-345. doi: 10.1177/1526924817731881.

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Conference Presentations Related to This Thesis

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Potter J, O'Leary M, Elliott R, Perry L, Aneman A, Brieva J, Cheng A, Seppelt I, Herkes R and the COMFORT investigators. COMmunication with Families regarding ORgan and Tissue donation after death in intensive care (COMFORT) intervention: a multicentre pre-post study. The Australian and New Zealand Intensive Care Society (ANZICS)/Australian Confederation of Critical Care Nurses (ACCCN) 42nd Annual Scientific Meeting on Intensive Care, Gold Coast, October 2017.

Potter J, Perry L, Elliott R, Kelly M, McKay, L. Evaluation of an innovative simulation workshop in communication skills to lead the family donation conversation. The 12th Congress of the World Federation of Critical Care Nurses, Brisbane, April 2016. Connect The World of Critical Care Nursing 2016;10(2):54.

Potter J, Perry L, Elliott R, Kelly M, O'Leary M. Training methods for health professionals to lead conversations concerning deceased organ donation: literature review. The ANZICS/ACCCN 39th Annual Scientific Meeting on Intensive Care, Melbourne, October 2014.

Potter J, Perry L, Elliott R, O'Leary M. Training methods for health professionals to lead conversations concerning deceased organ donation: literature review. NSW Organ and Tissue Donation Service Forum, Sydney, September 2014.

Potter J, Perry L, Reed C, Herkes R, COMFORT study management committee. COMmunication with Families regarding ORgan and Tissue donation after death in intensive care (COMFORT) study. The Prince of Wales Hospital Nursing Symposium, Sydney, May 2014.

Potter J, COMFORT study management committee. COMmunication with Families regarding ORgan and Tissue donation after death in intensive care (COMFORT) study. Transplant Nurses Association National Conference, Sydney, October 2013.

Potter J, COMFORT study management committee. COMmunication with Families regarding ORgan and Tissue donation after death in intensive care (COMFORT) study.

The ANZICS CTG 15th Annual Meeting on Clinical Trials in Intensive Care, Noosa, March 2013.

Potter J, COMFORT study management committee. COMmunication with Families regarding ORgan and Tissue donation after death in intensive care (COMFORT) study. NSW Organ and Tissue Donation Service Forum, Sydney, November 2012.

Other Published Works Related to This Thesis

Potter J, O'Leary MJ. Obtaining consent for cadaveric organ donation in Australia. *Internal Medicine Journal* 2013;43(7):737-39. doi: 10.1111/imj.12191.

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Abbreviations

AODR, Australian Organ Donor Register;

A-V, Audio visual;

CPD, continuing professional development;

CRF, case report form;

CST, communication skills training;

DCD, donation (or donor) after circulatory death;

DBD, donation after brain death;

DR, Designated requester;

ED, emergency department;

EOL, end of life;

FDC, Family Donation Conversation;

HCP, healthcare professional;

ICU, Intensive care unit;

MERSQI, Medical Education Research Study Quality Instrument;

NDD, neurological determination of death;

NR, not reported or unclear;

NS, non-significant;

NSW, New South Wales;

NURSE, Name Understand Respect Support Explore;

OD, organ donation;

OPO, Organ Procurement Organisation;

OSCE, Observed Structured Clinical Examination;

PEP, Professional Education Package;

PICU, Paediatric Intensive Care Unit;

RMS, Roads and Maritime Services registry;

RN, registered nurse;

SANOK, Senior available next of kin;

SFM, standardised family member;

SPIKES, Setting Perception Invitation Knowledge Emotions Summary and Strategy;

SP, standardised participant;

UK, United Kingdom;

US, United States

Glossary of Terms

This section provides definition for terms and phrases used in this project.

Term	*Definition*
Brain death	An historical expression for death determined by neurologic criteria where permanent absence of whole brain function has been shown on bedside clinical testing of brainstem reflexes and apnoea, or additional radiological imaging of brain perfusion if unable to perform clinical tests (ANZICS Death and Organ Donation Committee 2019; Kotloff et al. 2015). In this thesis the term 'brain death' will be used interchangeably with the more correct term of neurologic determination of death.
Donation after circulatory death	Donation or Donor after Circulatory Death (DCD) refers to Modified Maastricht Category III controlled DCD (cDCD) cases within the hospital, when withdrawal of life-sustaining therapy is planned and followed by expected circulatory arrest (Thuong et al. 2016). In Australia, circulatory determination of death requires 3 to 5 min absence of circulation (ANZICS Death and Organ Donation Committee 2019).
Designated requester	A healthcare professional such as an intensive care specialist doctor "intensivist", experienced critical care nurse or social worker selected by their department, and who had completed or was completing mandatory national training (Professional Education Package, core and practical modules) and the New South Wales Simulation Training Workshop.
Donor-eligible patient	A patient considered to be a potential organ donor because of a devastating brain injury or lesion or a patient with circulatory failure, and apparently medically suitable for organ donation. Also, their clinical condition was suspected to fulfil neurologic criteria for death, or the cessation of circulatory and respiratory functions was anticipated to occur within a timeframe that would have enabled organ recovery. Termed a *donor-eligible patient* in this thesis.
Healthcare professional	A term including specialist intensive care doctors such as intensivists; trainee doctors such as registrars or residents; registered nurses, specialist critical care nurses, donation specialist nurses; and social workers.
Managing intensivist	Senior intensive care doctor/staff specialist or an advanced trainee (fellow) / senior registrar who had passed the Fellowship exam, responsible for the clinical management of the donor-eligible patient.

Term	*Definition*
Medically suitable	A potential organ donor was deemed medically suitable to donate one or more organs for transplantation if they did not meet medical exclusion criteria. These criteria included transmissible diseases such as HIV, recent or metastatic cancer other than primary cerebral cancer, and untreated systemic infection (donor/organ reasons). (Definitions from the national DonateLife Audit, the tool used in classifying hospital deaths retrospectively for reporting). Medical suitability exclusions were divided into "donor/organ" and "system" categories. Examples of system reasons include potential organ donors who were not anticipated to become brain dead and were not eligible for the circulatory death pathway either due to age or were anticipated to die outside a timeframe that would enable organ recovery; or lack of recovery teams; or of a suitable recipient(s) (Dominguez-Gil et al. 2011).
Unregistered subsample	The subsample including cases where the registers (NSW Roads and Maritime Services registry (driver licence) and the Australian Organ Donor Register) had been checked and no details had been found of an individual's registered donation preferences, or when the registers were not accessed because individuals were aged 16 years or less.

Abstract

Introduction: Demand for organs for transplantation exceeds supply; family consent rates for deceased organ donation could increase with improving communication skills of the healthcare professionals responsible for the family donation conversation.

Aim: To implement and trial a 'best practice' approach for offering deceased organ donation, to test whether the intervention increases the proportion of families providing consent; to examine families' decision-making experiences and rates of decisional regret three months later.

Methods: A multicentre mixed methods study with a pre-post intervention component was performed in nine NSW intensive care units. Compared with pre-intervention controls, a prospective cohort of families of potential deceased organ donors were assigned to the "COMFORT" intervention. Families were offered bereavement aftercare and an interview 90 days later to provide their experiences.

The primary end point was the proportion of families consenting to organ donation in patients without registered donation preferences. Secondary end points were healthcare professionals' adherence rates to the intervention, identification of predictors of the donation decision, and the proportion of families regretting their donation decision at 90 days. Descriptive statistics and logistic regression modelling were used to examine outcome data, with content analysis for free text responses.

Results: In total 417 patients were enrolled in the study. For patients without registered donation preferences consent was obtained in 87 of 164 (53%) cases during the intervention period compared to 14 of 25 (56%) cases pre-intervention ($p = .83$). The odds of obtaining consent during the intervention period relative to the pre-intervention period were 1.13, (95% CI, 0.48-2.63); $p = .78$.

Characteristics independently associated with family consent were identified: when families first mentioned organ donation (OR 4.34; 95% CI, 1.79-10.52; $p = .001$), presence of an independent designated requester (OR 3.84; 95% CI, 1.35-10.98; $p = .012$), the number of donation conversations per case (OR 3.35; 95% CI, 1.93-5.81; $p < .001$), and patients of non-Christian religion (OR 0.18; 95% CI, 0.04-0.91; $p = .038$). Interviewees overwhelmingly ($n = 127$, 97%) agreed their decision had endured at three months after enrolment.

Conclusion(s): Uptake of some components of the COMFORT intervention was incomplete, and while the intervention as a whole did not significantly increase the organ donation consent rate, some elements exerted significant effect. Further work is required to identify those best practice elements that are most important and supportive for families making donation decisions; to determine strategies that might improve uptake and adherence by managing teams.