

The Rural Research Capacity Building Program 2010
Final report for research project:

Are there barriers to rural families having
discussions about their organ and tissue donation
wishes?

Principle Researcher:

Mary Campbell, Clinical Nurse Specialist
Organ and Tissue Donation.
Northern NSW Local Health District
Tweed Heads Hospital
Telephone: 0421612186
Email: Mary.campbell@ncahs.health.nsw.gov.au

Table of Contents

Content	Page Number
Acknowledgements	3
Glossary of Terms	4
Abstract	5
Key Words	5
Executive Summary	7-8
Introduction	8
Background and Literature review	8-13
Aims of the research	13
Method	14
Participants Recruitment and Demographics	14-18
Findings	18-23
Discussion	23-24
Strengths and Limitations	24
Conclusions and recommendations	25-26
References	27-28
Appendix A – Initial Contact Letter	2
Appendix B – Participant Information Sheet	30-32
Appendix C – Participant Consent	33
Appendix D – CSSU Flyer	34
Appendix E – SCU Flyer	35-36
Appendix F – U3A Flyer	37-38

Acknowledgements

The author would like to acknowledge:

- The participants who freely gave their time and shared their honest experiences in initiating family discussions.
- Emma Webster, Rural Research and Executive Support Officer Health Education and Training Institute, Rural Directorate, for providing invaluable direction and faith in the novice researchers journey.
- David Schmidt, Rural Research Program Officer, Health Education and Training Institute – Rural Directorate, for always having the answer readily available.
- Dr Catherine Hawke, Senior Lecturer in Rural Health, Medicine, School of Rural Health, University of Sydney, the mentor, who gave advice and reassurance to the novice researcher.
- Val Johnstone, Area Clinical Practice Coordinator / Research Ethics Officer / Quality Awards Coordinator, North Coast Area Health Service, who's assistance made the navigation of ethics submission achievable.
- Chalta Lord, a research colleague from NNSW LHD and a member of the 2010 research group, who shared dialogue, emails and coffee meetings that made the research journey more manageable.
- The NSW Organ and Tissue Donation Agency, and NCAHS, for their support in authorising the participation in the research project.

Funding for this project was made available by the Health Education and Training Institute: Rural Directorate Rural Research Capacity Building Program of the NSW, previously known as the Institute of Clinical Services and Teaching.

Glossary of Terms

AHS	Area Health Service
AODR	Australian Organ Donation Register
Clinician	A professionally qualified, registered healthcare worker in direct patient contact
CSSU	Central Sterilising Supply Unit
DSN	Donor Specialist Nurse
HETI	Health Education and Training Institute
HREC	Human Research Ethics Committee
NCAHS	North Coast Area Health Service
NNSW LHD	Northern New South Wales Local Health District
NRA	National Reform Agenda
MNC LHD	Mid-North Coast Local Health District
ODM	Organ Donation Model
P&CA	Parent and Citizens Association
RRCBP	Rural Research Capacity Building Program
RTA	Road Traffic Authority
SANOK	Senior Available Next of Kin
U3A	University of the Third Age

Abstract

Are there barriers which prevent rural families from discussing their organ donation wishes?

Background: Organ transplantation is the definitive treatment for many patients with end-stage organ failure. Australia however, has a persistently low donation rate, which results in many Australian's dying before transplantation.

In New South Wales (NSW) in 2011, 31% of families for whom consent was requested, declined permission for their loved one to become an organ donor. However, evidence suggests that when families have had a memorable discussion about their organ donation wishes, they are more likely to support their loved ones wish to become an organ donor.

Aims:

1. To identify if barriers exist which prevent or inhibit families from holding a memorable discussion about their organ donation wishes.
2. To identify factors that facilitates organ donation discussions within families.

Methods: Four focus groups were conducted in rural NSW, incorporating a continuum of ages from senior school children to retired seniors. The focus groups included year 10 and 11 students, sterilisation technicians employed in the Central Sterilizing Supply Unit (CSSU) of a local hospital, university lecturers from Southern Cross University (SCU) and members from the University Third Age (U3A).

The senior students and the sterilisation technicians had been involved in an organ donation education session prior to participating in the focus group, while the university lecturers and members of U3A had not been involved in an educational session prior to participating in the focus group. The focus group data was transcribed and coded to identify key themes using an interpretative phenomenology process.

Results: The identified barriers to family discussion about organ donation wishes were lack of knowledge about organ donation, geographical distribution of family members, the hectic pace of family life and age. The findings also showed that school children and adults were able to initiate family discussion with ease once they had been involved in an education session.

Conclusion: Despite the barriers, family discussions are facilitated when individuals have participated in an education session and given the opportunity to ask questions.

Key Words: Organ donation, family discussion.

Executive summary

Background

Organ transplantation is the definitive treatment for people with end stage organ failure. Recent significant advancements in both immunology and surgical techniques have taken organ donation and transplantation from an experimental level to being the therapy of choice for people who suffer with end stage organ failure. Unfortunately, Australia, like many other nations has an persistent shortage of available organs for transplantation, resulting in prolonged waiting times during which time the potential transplant recipients carry an increased risk of further deterioration in their health and death.

When organ donation does takes place, there is a requirement in Australia to obtain consent from the immediate family, irrespective of the potential donor registering their intention on the Australian Organ Donation Register (AODR) to become an organ donor. Australia's family consent rate is low, with approximately half of all families approached for organ donation, denying consent. It is known that when families have had a memorable discussion about their organ donation wishes, families are more likely to support the wishes of their loved one.

Aim

This study aimed

1. To identify barriers which prevent or inhibit families from holding a memorable discussion about their organ donation wishes.
2. To identify factors that facilitates organ donation discussions within families.

A literature review demonstrates that there are many factors which can influence an individual's decision to become an organ donor. These factors include, concerns about bodily integrity, institutional mistrust, the fear of bringing on death prematurely, and mistrust of the organ allocation system. Many individuals who do make a decision to become an organ donor subsequently fail to discuss and convey their wishes with their family. This vital step impacts enormously on potential donor numbers in Australia, as the immediate family of the potential donor are always asked to give their consent before the donation can proceed. Evidence suggests that when families know their loved one's wishes, the family are more likely to support the organ donation wishes of their family member.

Approximately 50% of Australian families refuse organ donation for their loved ones. As a result many people on the Australian organ donation waiting list do not have the opportunity to receive an organ transplant and die.

To save more lives we need to increase the rate that families consent to organ donation. To do this we need to encourage more families to discuss their organ donation wishes. The identification of barriers and facilitators to discussion is a vital step in this process of establishing evidence for effective interventions to promote family organ donation discussions.

Methodology

This qualitative study was based on interpretative phenomenology principles, which aimed to describe accurately the lived experience of the participants within the focus groups. The

principle investigator conducted four, age specific focus groups in rural NSW, to explore the barriers and facilitators of memorable family discussions of organ donation wishes.

Transcripts were analysed for emergent themes using an inductive approach to thematic analysis, where the themes emerged from the data and enabled an open coding process and triangulation rigor.

Results

This study identified three recurrent themes which inhibit family discussion about organ donation wishes within families. These include

- A lack of information prevented individuals from initiating family discussions about organ donation wishes.
- The geographical distribution of families and the hectic pace of family life can inhibit family discussions about organ donation wishes.
- Age can influence a person's willingness to initiate family discussions about organ donation.

This study also found that school children initiated organ donation discussions with ease once they have been involved in an educational awareness day. The study also found that when groups of people participate in an education session about organ donation, where information is provided and participants are given the opportunity to ask question, which in many instances allows participant to dispel existing myths and concerns that they may have about organ donation, participants are more likely to initiate a family conversation about organ donation wishes.

This study highlighted just how powerful community education session are in breaking down cultural barriers to organ donation and in providing confidence to individuals to initiate a conversation in a household where it is know that the general attitude to organ donation is not supported.

Conclusion:

Findings from this study demonstrate that there are barriers to family discussions about organ donation wishes, and highlighted the importance of providing educational sessions to the general community about organ donation. Educational sessions in this study were the catalyst that initiated family conversations about organ donation wishes, by providing participants with the knowledge, and confidence to raise the subject within families even when it was known that organ donation was not supported, or where traditional cultural resistance had previously existed.

A challenge exists to engage social and community groups to allow educational sessions to take place. It is relatively easy to engaged retired groups such as Rotary, PROBUS, and Lions clubs, although attendance by participants at these meetings often falls when the presentation topic involves end of life decisions. It can be extremely challenging to engage wider community groups such as essential services, education groups, and small businesses.

Recommendations:

This study identified that school children initiate family conversations about organ donation after being involved in an educational event, irrespective of family structure. The researcher

believes this finding identifies an area of attentive minds which could be engaged in an age appropriate way to facilitate family discussions about organ donation wishes. This strategy will have a lasting gradual effect in changing community attitudes and encouraging family discussions about organ donation wishes. This study strongly supports the incorporate of organ donation education into the school curriculum nationally.

Introduction

This report is the culmination of a two year research grant funded by the Health Education and Training Institute: Rural Directorate. It is intended that this report will inform health administrators of the importance of continuing community education and the impact that face to face education has in assisting individuals to have family conversations about their organ and tissue donation wishes.

The report explains why there was a need to undertake the research and how it was undertaken. The report concludes with recommendation and future research opportunities to augment this current research.

The purpose of the research was to identify barriers which prevent or inhibit rural families from holding a memorable discussion about their organ donation wishes, while also identifying the factors that facilitates organ donation discussions within families.

Search Strategy:

A literature review was undertaken using Clinical Information Access Project (CIAP) and databases searched were the Cochrane Collaboration, Medline, Cinahl and Embase. Search terms included, family discussions and organ donation. Dates chosen were from 2000 to the present.

Whilst there is extensive material related to the many aspects of organ donation, including attitudes towards organ donation, influences of media, and types of requesting styles, there is little written on families holding a discussion about organ and tissue donation wishes. Due to limited results a snowballing technique was used to obtain references from the reference lists of the limited material available.

The principle investigator also sought assistance from a health librarian to ensure a thorough search had occurred. This secondary search did not provide any additional information.

Background and literature review

Organ donation is the definitive treatment for people with end stage organ failure in the 21st century⁽¹⁾, due to improvements in both organ transplant immunology and surgical techniques over recent decades⁽²⁾. There is also an increasing incidence of end stage organ failure worldwide⁽³⁾. Like many other nations Australia has a significant discrepancy between the numbers of people on transplant waiting lists, and the number of organs being donated for transplantation⁽¹⁾.

The lack of available organs for transplantation in Australia results in an average waiting time of between six months and four years for patients on the transplant waiting list. In 2011, 35% of patients listed for a liver transplant were removed from the listing due to death, becoming too sick, tumour progression and infection⁽⁴⁾. The average waiting time for the 1158 patients listed for a kidney transplant in 2011, was between 3.6–19.2 years⁽⁵⁾.

In 2008, the National Reform Agenda (NRA)⁽⁶⁾ was implemented to address the factors that contribute to low donation rates in Australia. The twin objectives of the NRA are to increase the capability and capacity of the health system to maximise donation rates, and to raise community awareness and stakeholder engagement across Australia to promote organ and tissue donation, thereby improving the chances of Australians on the transplant waiting list of receiving an organ transplant.⁽⁷⁾

A community education program has been implemented as part of the NRA. The education program aims to provide clear, factual and relevant information, to ensure that the Australian community is provided with sufficient information to assist in making an informed choice, and to engage in family discussion about organ donation wishes. It is anticipated that increased community knowledge will lead to increase donation rates⁽⁶⁾. Community education will also assist to normalise organ donation discussions within families. This is extremely important because before organ donation can take place, family members of potential donors will always be asked for permission to proceed,⁽⁷⁾⁽⁸⁾ and the final decision is often influenced by whether the decision maker or family actually know the individual's wishes.⁽⁹⁾

There are a number of factors which influence an individual's decisions to become an organ donor. These include: having sufficient knowledge about organ donation and the processes involved, having an understanding of the concept of brain death, and having a desire to give an altruistic gift to save another person's life. There are also a number of factors that can influence a person's decision not to be an organ donor, including: lack of information, cultural and religious beliefs including the need to keep the body whole, fear of mutilation, distrust of the medical system, and fear of being declared dead prematurely⁽⁹⁾⁽¹⁰⁾. Irving et al (2012) identified relational ties, family influences, previous interaction with the health care system, and fear of an early organ donation process as major reservations about the process of organ donation, and therefore being influencing factors in organ donation decisions.

Thinking about death is difficult for many people as it can create feelings of unease, anxiety and discomfort. These powerful emotional feelings may become barriers to open conversations about death and organ donation and lead to avoidance of initiating a discussion about end of life wishes⁽⁹⁾. Other barriers identified in initiating this conversation include, the hectic pace of family living, and a lack of time when families do meet together to have discussions⁽⁹⁾. School students also report that it was difficult to communicate with their family about their own death and the death of a family member⁽¹¹⁾.

Knowing a family member's wish about organ donation has been shown to be the most powerful predictor of family consent, which in turn is determined by whether organ donation was discussed with family members⁽²⁾⁽¹²⁾. Only about half of all individuals who wish to be an organ donor have discussed their wishes with family members⁽¹³⁾. As a result about 50 % of

families often refuse to support the potential donor's wish. Even if the potential donor has registered an intention to become an organ donor⁽¹⁴⁾ on either the Australian Organ donation Register (AODR) or the Road Traffic Authority (RTA) ⁽⁹⁾. Consent is also less likely when there is family conflict, or when family members are not in complete agreement about donation ⁽¹⁵⁾.

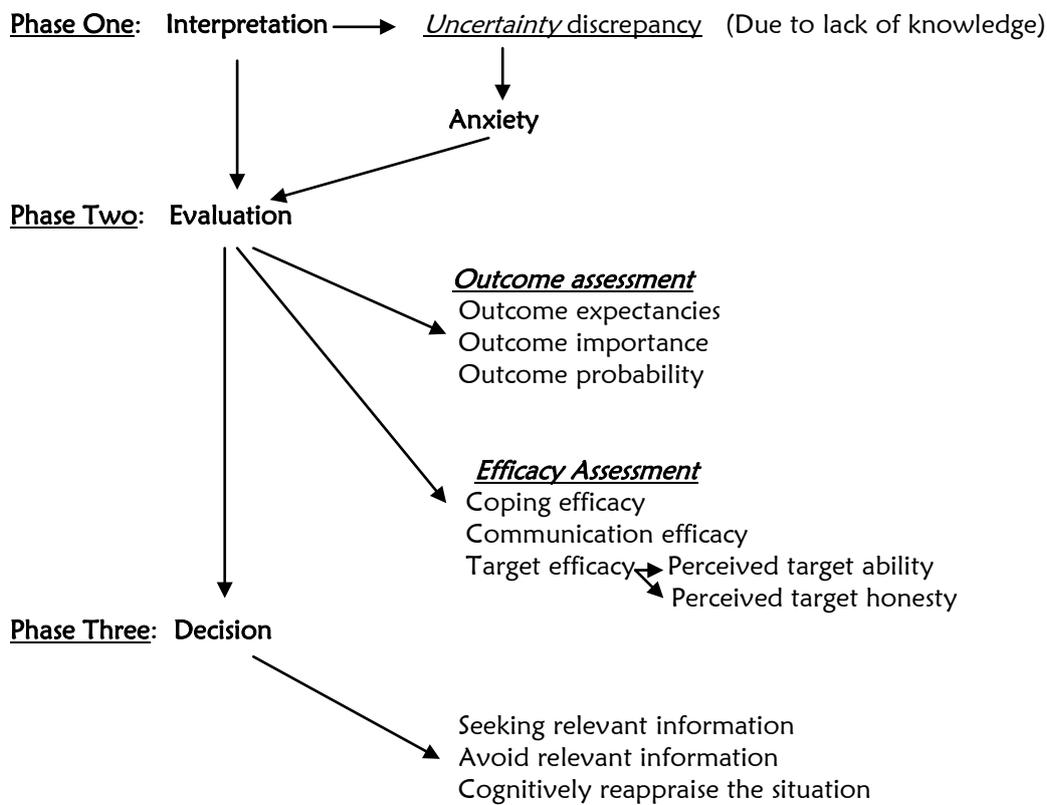
A study by McDonald et al⁽¹¹⁾ suggests that the factors that affect the willingness and ability to communicate with family members need to be identified. This is particularly important as participants in that study scored high on the willingness to communicate even though that communication had not yet taken place.

One theory that is helpful in understanding the process that individual's navigate to initiate a family discussion about organ donation is the Theory of Motivated Information Management (TMIM). Before proceeding with a description of the Theory of Motivated Information Management, it is important to clarify what is understood by the term information. Information is defined by as a stimulus from the person's environment that contributed to his or her knowledge or belief ⁽¹⁶⁾. Consideration must also be given to how families are defined. Previously families have been defined as individuals connected primarily through legal and biological ties. Significant changes have taken place in recent decades to this perception with families now being defined as groups of intimates who generate a sense of home and group identity and who experience a shared history and a shared future ⁽¹⁷⁾. It is also important to acknowledge that family interactions typically aim to foster harmony thereby avoiding conflict ⁽¹⁷⁾.

The Theory of Motivated Information Management (TMIM) proposes a three phase process of information-management in interpersonal encounters ⁽¹⁸⁾. The three phases are described as hierarchical in nature beginning with an interpretation phase followed by an evaluation and decision phase in a progressive manner. A number of assessments take place in the evaluation phase and these assessments affect choices made in the decision phase which in turn influences future evaluations.

An interpretation of the TMIM is diagrammatically represented in figure 1. The diagrammatical representation of the TMIM, is based on the researchers interpretation of the theory.

Figure: 1 Theory of Motivated Information Management –Diagrammatically represented



Phase One: Interpretation

In the initial interpretation phase an individual becomes aware that a knowledge discrepancy exists. This knowledge discrepancy creates a degree of uncertainty about an important issue, with the individual acknowledging that the degree of uncertainty is more than they desire. This discrepancy is labelled uncertainty discrepancy and it is the uncertainty discrepancy which creates a level of anxiety for the person ⁽¹⁹⁾. The presence of anxiety in an individual contributes to an individual moving to the second phase, the evaluation phase ⁽²⁰⁾.

Phase Two: Evaluation

In the evaluation phase expectations about the outcomes of an information search and perceived abilities associated with that decision direct behaviour. The theory of motivated information management suggests that individuals are more likely to seek information when they possess positive expectations about the outcome of the information search. ⁽²⁰⁾

The evaluation phase is influenced by two assessment components, *termed outcome assessment* and *efficacy assessment*. The outcome assessment and the efficacy assessments are further influenced by three additional assessment components each. Outcome assessment includes an assessment of *outcome expectancies*, *outcome importance* and *outcome probability*. Efficacy assessment is influenced by *coping efficacy*, *communication efficacy* and

target efficacy components. A description of the influences that each of the outcome assessments and efficacy assessments follows.

Outcome assessment

In the outcome assessment phase there is the belief that individuals consider their actions prior to selecting a strategy. The assessment is based on an assessment of the possible outcome of an action, where the individual assesses the cost and benefits of a particular information seeking strategy identified as *outcome expectancies*. Followed by an assessment of the outcome value of such a strategy, that is the importance of the expected costs and benefits, identified as *outcome importance* and assessment of *outcome probability*, where the likelihood that a particular strategy will result in the expected outcome. ⁽¹⁹⁾

The outcome processes allow individuals to assess the benefits and costs they expect from an information seeking strategy, as well as the importance, and probability of a particular strategy. It is suggested that outcome expectancy is the central variable, with outcome importance and outcome probability playing more peripheral roles ⁽¹⁹⁾.

Efficacy assessment

The second component of the evaluation phase, efficacy assessment is the extent to which individuals perceive themselves as able to successfully reduce the anxiety through such a search. Efficacy beliefs refer to an individual's perceptions of their ability or the ability of a target object or person to successfully perform the behaviour or produce an outcome ⁽¹⁹⁾

Afifi & Weiner (2004)⁽¹⁹⁾ has further developed efficacy assessment by suggesting three components of assessment that incorporate *coping, communication and target efficacy*.

Coping efficacy considers the individuals belief that they have the emotional, instrumental and other resources to engage in a strategy and manage the outcomes expected from the strategy under consideration.

Communication efficacy is where the individual believes that they possess the skills to successfully complete the communication tasks involved in the information management process. Communication efficacy is considered to be a critical component of the process in the theory of motivated information management.

Target efficacy contains two subcomponents which are termed *perceived target ability* and *perceived target honesty*. These two subcomponents represent the belief that the information target is able and willing to provide complete information. Both target efficacy components are important parts of the information management process. Afifi & Weiner (2004 p.179)⁽¹⁹⁾ suggest that "individuals are unlikely to seek information from targets who are not considered able to provide the information, whether because they do not have access to the information (*target ability*) or because they are not deemed as willing to provide it (*target honesty*)".

Afifi & Weiner 2004⁽¹⁹⁾ suggests that information seekers assess whether they have the ability to cope with the outcomes that they expect from initiating the information management strategy (*coping efficacy*), and whether they have the skills to engage in the communication activities required as part of the strategy (*communication efficacy*) and if a particular target is able to offer the information being sought (*target efficacy*).

Phase Three: Decision

The decision phase involves the selection of information-management strategies. Within the decision phase there are three general strategies for individuals motivated to manage uncertainty related anxiety. They include *seek relevant information, avoid relevant information or cognitively reappraise the situation*.⁽¹⁹⁾

Seeking relevant information can occur as a direct interaction in asking the target for information, however in the majority of social circumstances less direct means of seeking information takes place. These less direct methods can include talking around the issue, disclosing information in the hope of receiving reciprocal information, and relaxing the target⁽¹⁹⁾.

Instead of seeking relevant information, an individual may choose to *avoid relevant information*. This can include active avoidance, where an individual actively avoids information, or avoids a situation or persons who may offer relevant information. Passive avoidance occurs when individuals let the issue unfold without pursuing the environment or targets for clues. An individual may choose passive avoidance if they consider that the process of seeking information is too risky as a result of outcome assessments or efficacy beliefs⁽¹⁹⁾.

Cognitive reappraisal occurs when individuals reduce anxiety by making psychological adjustments that change the original need for information. Anxiety therefore is reduced as a function of cognitively altering the need for uncertainty management, instead of actually obtaining information.⁽¹⁹⁾

The theory of motivated information management begins with identification of a gap between desired and actual knowledge, creating an uncertainty discrepancy and anxiety about an important issue. The motivation to reduce anxiety triggers the assessment of various information management strategies to achieve an alteration in uncertainty related anxiety. Following the process of outcome and efficacy assessments, individuals choose a strategy that they consider the most appropriate, given physiological, social and behavioural concerns and cognitive limitations. This theory proposes a dynamic and fluid process that relies centrally on the cognitions and action of individuals⁽¹⁹⁾.

Aims of the Research

This study aims to identify

1. If barriers exist, which prevent families from holding memorable family discussions about their organ donation wishes?
2. To identify the factors that facilitates organ donation discussions within families.

The study incorporated participants who reside in the Northern New South Wales (NNSW) and Mid North Coast (MNC) Local Health Districts.

Method

A qualitative study was planned where participants were invited to participate in an unstructured focus group discussion. The focus groups supported small group discussions with groups of between five to ten people that aimed to explore specific issues regarding families holding discussions about organ and tissue donation. Participants were encouraged to talk and interact with each other to assist with exploring and clarifying individual and shared perspectives ⁽²¹⁾

Principal researcher:

The principal researcher is a hospital based Clinical Nurse Specialist (CNS), Donor Specialist Nurse (DSN) in Organ and Tissue Donation covering the newly aligned NNSW LHD. A component of the role, involves raising awareness in the community about organ and tissue donation and encouraging families to hold a memorable discussion about their organ and tissue donation wishes.

The researcher holds a Graduate Diploma in Critical Care. Training for the role of Donor Specialist Nurse, has been provided by the NSW Organ and Tissue Donation Agency. Training in research techniques has been through the NSW Primary Health Care Research Capacity Building Program (NSW PHC)

Ethics approval for the research was received from the North Coast Area Health Service (NCAHS), Human Research Ethics Committee (HREC) on the 28th July 2011: reference: LNR/11/NCC/52. Approval for an amendment to the study was approved by the NCAHS, HREC on the 11th January 2012.

The study sample included people who reside within the former North Coast Area Health Service (NCAHS) which has since been divided into two Local Health Districts (LHD). The Northern New South Wales Local Health District (NNSW LHD) and Mid North Coast Local Health District (MNCLHD). Collectively the NCAHS covered an area of 35,570 square kilometres extending from the Queensland Boarder, Southward to Port Macquarie. The NCAHS also extended westward from the coast to the Great Dividing Range. The NCAHS is the fastest growing rural Area Health Service (AHS) in NSW. The total estimated residential population of NCAHS in 2006 was 479,544 and it is projected to increase by 7% to 511,146 by 2011. ⁽²²⁾

Sampling

A maximum variation sampling⁽²³⁾ technique was employed to recruit groups of participants. The researcher aimed to incorporate a range of chronological ages and educational attainment within the focus groups. The four focus groups included senior school children, sterilisation technicians who hold a Certificate 111 in sterilization services, university lecturers, and retired seniors. Contact was made with each of the groups by passive snowballing. ⁽²⁴⁾ A key person was contacted in each group, who facilitated the distribution of a flyer or information packs to potential participants.

In this research project, the senior school students, and the hospital based sterilisation technicians participated in an education session about organ and tissue donation prior to

participating in the focus group discussion. The information provided encouraged participants to discover the facts about organ and tissue donation, to make a decision that was right for the individual, and to discuss their wishes with their family and friends. The educational presentations according to the theory of motivated information management would have highlighted a potential uncertainty discrepancy in the participant's knowledge of their family member's wishes. This uncertainty discrepancy would have created anxiety among participants thereby initiating the three phase process of information management, facilitating a family discussion.

The senior school children who participated in the focus group discussion were the student leaders who helped to facilitate the education awareness day, titled "Do you have a heart?" The student leaders were invited to participate in the focus group by initially making contact with the lead teacher who was the principle facilitator of the awareness day. The lead teacher distributed information packs to the student group which included an invitation letter (Appendix A) the information sheet (Appendix B) and consent form (Appendix C). This information was taken home for parental approval and consent, as all senior school students were aged between 14 and 16 years.

The hospital CSSU workers were invited to participate by initially contacting the Nursing Unit Manager (NUM) of the CSSU department. The NUM displayed an invitation in the tea room (Appendix D), and the invitation letter, information sheets and consent forms were provided to participants wishing to participate by the NUM.

The university lecturers and the retired seniors were asked if they would like to be involved in the research project by snowballing sampling, where contact was made with these participants from within the community. Flyers were displayed in the university lecturer's tea room (Appendix E) and at a University of the Third Age (U3A) meeting (Appendix F). Invitation letters, information sheets and consent forms were distributed via the group's main contact person.

The university lectures and the members of the U3A had not been provided with an educational session prior to conducting the focus group discussion. They may however, have been exposed to recent television advertisements or newspaper stories, which highlighted the importance of family discussion in relation to knowing family member's organ donation wishes.

A group of office workers from a local accounting firm were also invited to participate, however despite initial verbal support, no follow up contact was made with the researcher.

Written consent was collected from all participants at the focus group meetings. Participants were encouraged to ask any questions about the research project prior to the commencement of the focus group discussion. Each participant was provided with a copy of their consent form. Participants were again reminded that participation in the project was voluntary and they were free to withdraw from the project at any stage prior to the final data processing and analysis. As data was de-identified, there would be difficulty withdrawing transcriptions from the cohort after data processing and analysis.

The recruitment of the retired seniors from the U3A, involved the researcher initially speaking to approximately 80 retired seniors about participating in the focus group. It was anticipated by the group leader that there would be a response rate of at least 20 participants. However, only five members responded to the invitation.

The setting for the focus groups varied due to the diversity of the participants. The locations were chosen:

- In consultation with the group leader's to facilitate convenience for participants.
- In an environment that participants were familiar with.
- The selected venue was appropriate to conduct an interview without disruption.
- The time was chosen by the leaders to accommodate convenience, with school, work and life commitments.

The selected venue's included a high school meeting room for senior students, an area specific tea room for the sterilisation technicians, a lecture room for the university lectures and a service club meeting room for the retired seniors.

At the senior school student group the lead teacher was present in the meeting room but did not participate in the group discussion until saturation of responses had occurred from students. The President of the schools Parents and Citizens Association (P&CA) also attended, refraining from the discussion until students had reached a saturation of responses. The President specifically asked to attend the focus group, but was not related to any of the children in the room.

A trial focus group and pilot of focus group technique was conducted on the 4th October 2011, prior to facilitating the first focus group meeting. Participants known to the researcher were invited to participate. Following the trial, a self-critique of the interview technique and lead questions took place resulting in the researcher modifying interview techniques based on listening to the recorded trial. The researcher felt that the lead questions were adequate in prompting a group discussion, and that the principle investigator was able to adequately conduct a focus group discussion and use the digital recording equipment. The four focus groups were conducted and facilitated by the principle investigator. The duration of each focus group was from 30 to 60 minutes, with a mean interview time of 42 minutes. Participants were provided with light refreshments, and the university lecturers were provided with a \$20.00 iTunes[®] gift voucher as an additional incentive to gain engagement in the study, and in appreciation of their time and contribution. A copy of the transcripts was available to the participants, but all participants declined this offer.

Initially, it was planned to conduct four focus groups, with an option to conduct an additional focus group if saturation of themes did not occur. At the completion of the second focus group a clear repetition of themes occurred. The researcher held discussions with a mentor to discuss the value of continuing with focus groups that had been provided with an

educational session. It was decided to submit a variation to Human Research Ethics Committee (HREC) thereby including individuals who had not been provided with an education session prior to participating in the focus group. The amendment was approved by the NCAHS, HREC on the 11th January 2012, resulting in the incorporation of university lecturer's and members of the University of the Third Age. All focus groups were conducted by the principle investigator.

The researcher used an inductive approach to thematic analysis, whereby the themes emerged from the data. As the principle investigator was a novice researcher, once the interviews had been transcribed and analysed for emergent themes, to enable an open coding process. The investigator submitted all code books to the investigators research mentor, ensuring thematic consistency and research triangulation. All coding and analysis was completed by hand.

Focus group demographics

The following provides a brief description of the individual group makeup, to help contextualise the context of the group discussions.

Teenage school children: A lead teacher at the rural school had previously had a personal family experience in organ donation. As a result of this experience the teacher held the belief that there was a need to incorporate organ donation awareness into the educational experience of children. The teacher's quest to achieve this outcome resulted in contact being made with the researcher as an expert in organ donation. This resulted in the researcher being involved in the development and implementation of an educational day for all levels of school children from within the Nambucca Valley in rural NSW. This educational day showcased a number of learning mediums to explore information and knowledge about organ and tissue donation. The learning mediums included art, music, play writing, acting, rap dancing, and poetry. The participants in the focus group were the student leaders who designed and directed many of the learning activities displayed on the educational day. There were 10 participants aged between 14 and 16 years. There was one male participant and nine female participants. Six students were from year 10 and four students were in year 11. Seven students were from two parent families, two students were from single parent families and one student lived with a grandparent.

Sterilisation Technicians, Central Sterilizing Supply Unit (CSSU): The researcher's role as a Donation Specialist Nurse in the NNSW LHD, involves providing community information and education related to organ and tissue donation. The researcher has provided various hospital departments with the opportunity to learn about organ and tissue donation, encouraging participants to hold a family discussion about their organ donation wishes. The CSSU were one of the hospital units to which education and information had been provided. There were six CSSU participants who were aged between 21 years and 58 years. There was one male and five female participant's whose occupational title is sterilisation technician. A sterilisation technician is a person who works in a hospital or medical facility sterilising and cleaning medical instruments used by physicians and nurses. A sterilisation technician is required to complete a Certificate 111 in Sterilisation Services⁽²⁵⁾

University lecturers: There were nine university lecturers from a Health Science Faculty. Participants were aged between 24 years and 58 years. There were two male and seven female participants. Educational demographics were not collected from this focus group. The university lecturers were not provided with an educational session prior to participating in the focus group. They may have been exposed to information about organ donation through the DonateLife advertisements that had been screened via television and print media.

Retired seniors: Members of University of the Third Age (U3A) Northern Rivers: The University of the Third Age (U3A) is a non-profit, worldwide movement, allowing older people to learn new skills from each other in a friendly non-political, non-religious atmosphere. U3A provides an opportunity for like-minded people, to exercise their mind and body at their own pace. It is suggested by U3A that keeping your mind active helps you enjoy your retirement even more ⁽²⁶⁾. Five members from U3A Northern Rivers participated in the focus group meeting. Participants were aged between 73 years and 80 years. There were two male and three female participants. The U3A participants were not provided with an educational session prior to participating in the focus group. They like all participants in the focus groups may have been exposed to information about organ donation through the DonateLife advertisements that had been screened via television and print media.

Instrumentation:

The focus groups were recorded using a 2 Gb Pulse smart pen as the principle recording device and a second digital recorder as a backup device. The information on the smart pen was transferred into a password protected electronic audio file on a secure drive, after which the recording was deleted. The backup digital recorder had all recordings deleted once transcription was complete.

Findings

Three major themes were identified after an analysis of the transcripts. The recurrent themes were

- A lack of information prevents individuals from initiating family discussions about organ donation wishes, and education sessions were identified as the catalyst in initiating family discussions.
- The geographical distribution of family members and hectic pace of life can inhibit family discussions about organ donation wishes.
- Age can influence a person's willingness to initiate family discussion about organ donation.

This study also found that school children and adults initiated organ donation discussions with ease once they had been involved in an educational event or session. Education sessions appear to be the catalyst in initiating family discussion about organ donation wishes as it provided participants with knowledge, an opportunity to ask questions, and highlights the importance of knowing their families wishes.

Theme one:– “People can’t talk about what they don’t know” (ST-1). Lack of information prevents individuals from initiating family discussions about organ donation wishes.

A lack of information made it is difficult to initiate a conversation with adult children. *“it is difficult for us to say, well look we think you should consider donating your organs because there is a shortage of them, but we can’t tell you what’s going to happen”* (with the organ donation process) U3A-5

U3A-5, explained that in his working life he had worked where autopsies had taken place and that the body was chucked around. U3A-5 was of the belief that *“organ transplant is a bit like that, like oh well we’ll take this bit and that bit”*. This perception had inhibited family discussion. Fear that *“if they (the potential donor) say “yes”, they don’t know what is going to happen even though they are dead like”*.

One participant reported that she had tried to raise it with her adult children,

“One child very uninterested and the other one said “we will never need to know”. “They are rejecting discussing it, because of lack of information and denial on behalf of my children”. (U3A -1) (Denial of the death of their mother)

Another participant described the difficulties in initiating a family discussion with her children.

“I am constantly seeing the donation forms and I am constantly taking them home to give them to my boys, but I never quite get there. Somehow the forms never get into their hands. Now that I have been here and heard a few of the criteria you need to meet ahm, I will try and address it again” (ST-3)

Adults also had difficulty in having conversations with older parents due to misinformation.

“I have had the discussion with my parents; they think they are too old. Their perception is that organ donation is just heart and lungs”. (SCU-5)

Education sessions were identified as the catalyst in initiating family discussions. *“Without having that discussion here, I wouldn’t have thought anything about it”* (ST-1)

This theme was further supported when participants engaged in a group discussion.

“A lot of families out there don’t know much about organ donation. Yeh, people have their own ideas about what it is and 90% of that is wrong. We all did before this education session” (ST-4)

It’s the kind of thing that slips your mind, until it knocks on your door (ST-5),

The effect of being involved in an education session was described by one participant who for cultural reasons traditionally did not support organ donation. The participant explained:

“I’ve been down that track with a few of my relations, where I have been the one who’s been left to deal with ahm them coming to their end of their life and they wanted to donate

their organs and I said no". "That's just my way, that's the way I've been brought up; it's quite spiritual for us. Of course the world is changing". (ST-2)

The education session was the catalyst in initiating this conversation with the participant's husband, which was prompted by concerns about the participant's grandchildren.

"I said well because of our grandchildren, I said what if something could help them someday, you know that's where I'm looking from and with that....he goes you can't donate mine and I said no, everyone's got their own opinion, but would you donate mine? (ST-2)

This participant some weeks later also raised it with her daughter. The participant reported that her daughter responded by saying *"I didn't think you would go for that mum. You have never walked down that track before".* The participant responded *"I have been starting to think about it, only because of the kids, so not quite there yet, but it's still in the mind"* (ST-2)

ST-6 stated that the education session was responsible for bringing *"up a lot of discussion in my family, I explained to (my husband) and mum that you have to be on life support and they didn't know that"*

Some participants from the university lecturers group had initiated family conversations as a result of seeing media

SCU-6 had the discussion with her parents following seeing a segment on a television program, 60 Minutes (about organ donation). *Mum and I said yeh yeh. Dad was not so sure; he said "what if I have an open casket"; he thought about it, so it took a while, it wasn't straight forward. He thought through the process and said yes"*

SCU- 7 had the discussion with her husband after viewing the advertisement on television *"We made a funny joke of it emphasising the Ok"*(part of the advertisement)

The senior school children all reported initiating a family discussion about organ donation, following the education activities and awareness day. Lack of information was not identified as a barrier in this cohort. Predominantly family discussions were initiated by the participants, but on other occasions they were initiated by siblings who participated in the school awareness day.

"We sat down at the dinner table and he (participant's sibling) had been talking about it the whole afternoon, like how it was a good day and everything and he sat down at the table and said, "like mum are you an organ donor"? And she was like "yeh, I've ticked it on my licence". And he was like "yeh but are you gonna donate your organs when you die". She was like "yeh of course", and he was like cause I am. And he's 11 and he was asking everyone, he wanted to know". (SS-1)

Participants of the senior school group reported initiating conversations outside of the family home amongst friends from sporting groups. One of these conversations took place as a result of the netball team wearing the Zaidee's rainbow shoe laces in a netball grand final. These shoe laces had been acquired by the students as part of the "Do you have a heart?" education day.

"Everyone was watching, like what's on their shoes and they realised it was the laces". "I explained it to all my friends and they were" "oh my god it is just so cool". What a brave

little girl and then they were like where can I get a pair of those shoe laces, and then they were like, I want to donate my organs one day” (SS-10)

Another participant reported that the education day resulted in a change of opinion. The participant reported that her mother did not support organ donation, resulting in the participant also deciding not to be an organ donor.

“I know my mum isn’t donating and I wasn’t real keen either, ‘cause I had the idea that I wanted to be buried whole or whatever. But after the day when I saw what they go through, they need them and I don’t when I’m dead so I decided I would. My mum knows that but she’s still not keen on doing it” (SS-8)

A parent requested permission to attend the focus group. The parent is the President of the Parent and Citizens Association (P&CA). The parent only contributed to the focus group discussion following saturation of discussion by the senior school children. The parent reported that her children had initiated conversations about organ donation as a result of the educational awareness day.

“I wasn’t in attendance on the day, I had other things I had to attend to, but my two children who are in kindergarten and year 3 came home and discussed it, and had so many questions for about half an hour. I had to sit and answer all those questions, and it was all very positive. Being such a difficult subject to talk with young kids about, it was quite good”. (SS-Parent)

Theme Two - “Life’s too busy, I see the kids a couple of times a week, sit down and have dinner most Sundays to discuss what is happening in our lives throughout the week, and I just think life’s got too busy” (ST-2)

The geographical distribution of family members and hectic pace of life can inhibit family discussions.

Geographical distribution of families also affects family discussions about organ donation wishes in the university lecturer’s cohort and members of U3A. Senior school children do not seem to be affected by this barrier.

The geographical distribution of families can result in family members “*not meeting up very often*” (SCU- 1).

“My sister died last week: this event was the catalyst in the family meeting up and in stimulating family discussion about end of life wishes between family members. Discussions involved organ donation wishes amongst family members. The family realised they should have discussed it much sooner”. (SCU-1)

SCU 2 reported, “*My children have grown up, one lives in Canberra and one lives overseas. This was the main reason for not having the discussion. When I do catch up with them I haven’t thought of it*”.

The hectic pace of adult life, resulting in family members not seeing each other on a daily basis, appears to be a barrier to family discussions.

ST-4 explained “*I just went home from work and talked about it, that was it. I was doing all the talking and he just listened. I am undecided and I don’t think he has decided. When*

asked “what would be required to bring the topic up again”, ST-4 stated “*just me to open my mouth again.* ST-4 acknowledged that the shifts that she worked can reduce the opportunity for that discussion to take place.

In the senior school students cohort family structure and distribution did not appear to inhibit family discussion. Family discussions are often initiated by both parents and children about the school day activities.

“I just started talking about my day and I told her (students mother), and I just asked her if she was an organ donor and she said yeh, and we had a discussion about it. It was just me and my mum. And when I went to my Dads (house) I asked him. He said he wanted to be” (SS-4)

“Before the day I didn’t know that your parents could override your decision and all that kind of thing. I didn’t know and then after the day it was just fresh in my mind and I just had to ask” (SS-6)

“Ah I just got home and had my T shirt on and mum just asked me about it, and what I heard on the day and I just told her. And I asked mum if she was donating her organs and she said “yes” (SS-9)

“I don’t know about everyone else’s parents but my nan always asks me what I learnt at school today. And if you were learning about organ donation school as a subject then you can easily say “oh I learnt about organ donation today and like 50% of people are waiting for a kidney donation and I can help” (SS-5)

U3A participants did not find the distribution of family members a barrier and reported using the telephone to have important conversations. U3A-3 reported *“I wouldn’t have to wait for a family gathering. If I was on the phone and it went through my head I would just say like now listen, have you thought about what you are doing”*

U3A-3 stated *“I’m fairly outspoken, you talk about what you need to talk about. I lined them up one day and said whatever is working they are welcome to it. It’s on my licence”*. However U3A-3 reported *“my children know my wishes, but I don’t know my children’s wishes. They are aged 51 and 52”*.

One senior school student stated that she lived with her grandmother and while visiting her grandmother in hospital, raised the topic of organ donation.

“My nan was like I want to donate my organs, and I know L (Nan’s friend) wants to donate her organs and nan’s friend was there and he wanted to donate his organs, and I was like when I die I want to donate my organs and she was like alright then and continued to eat dinner” (SS-5)

Theme three: “My Grandparents believe they are too old” (ST-4)

Age can influence a person’s willingness to initiate family discussion about organ donation.

Age appear as a recurrent theme among the U3A cohort, parents of the university lecturers and grandparents a sterilisation technician.

“I raised it with my father, who said no one would want his body parts” (SCU-7)

“For the older people generation, it is a taboo topic, many don’t want to talk about it, it happens to other people”. U3A-1

This statement perhaps helped to explain the lack of interest by members of the U3A cohort in participating in a focus group discussion, despite being a group of retired seniors who actively seek learning on an ongoing basis. The group leader reported *“that anytime we talk about matters dealing with death and dying we see a significant drop in numbers (attending sessions), despite it being important information for us”*. (U3A-1)

This study also found that school children of all ages raise organ donation discussions within families without hesitation.

“Ahm I have four brothers and sisters and all of them had the discussion with me, like it wasn’t just with mum. They all came into my room and asked me, like are you gonna and stuff. They were saying how silly it was if you don’t. Like that afternoon that’s pretty much all we talked about like the whole afternoon was about it. It just continued on when we got home ‘cause we had the shirts on and it was like it was just a reminder” (SS-2)

Discussion:

This study identified that a lack of information, the geographical distribution of family members, hectic pace of family life, and age were barriers to initiating family discussions about organ donation wishes.

A lack of information prevented participants from initiating a family discussion about organ donation. It was suggested by participants that they could not initiate a discussion because they did not know what to discuss or it had not occurred to them to initiate a conversation. Participant felt that the involvement in an education session provided them with the knowledge to initiate family discussions about organ donation wishes. The education session was therefore instrumental in all participants subsequently initiating family discussions.

The hectic pace of life today limits the amount of time that families spend discussing issues like organ donation. Work demands and commitments of daily living can act as barriers and prevent family discussion about organ donation. Despite this the education session enabled participants to initiate a conversation thereby alleviating this barrier.

Age was also a barrier to family discussion about organ donation wishes. Retired seniors may consider that they are too old, or that their organs would not be of any use. Retired seniors often shy away from thinking about death and will often avoid information sessions which discuss end of life discussions. When retired people can be engaged the education session will provide accurate information often dispelling many of the myths and misconceptions that exist for this group of people. Retired seniors may be instrumental in initiating family discussions as they have a greater amount of time to ensure family discussion do take place,

The geographical distribution of family members was also a barrier to family discussions about organ donation wishes. Many young adults relocate from rural areas to larger metropolitan, interstate, or international areas for work or career development. This results in families

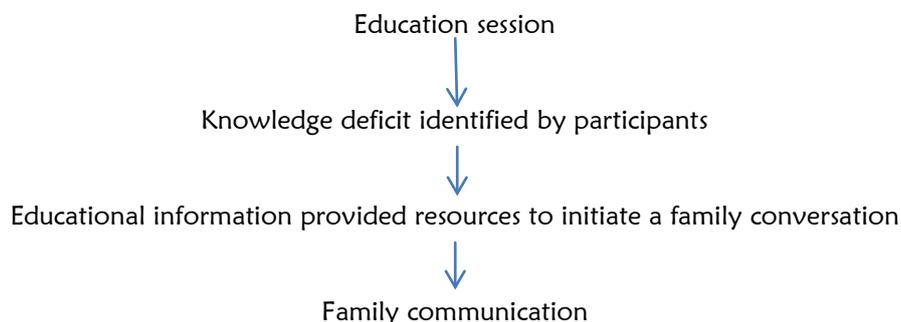
meeting up infrequently. When families do gather, organ donation is not a subject that is thought of for discussion.

This study found that when people have been involved in an education session, the participants subsequently initiate family discussions. Senior school children in this study did not identify barriers in initiating family discussions, and initiated family and social conversations about organ donation with ease once they had been involved in an educational awareness day. Similarly sterilisation technicians from a hospital CSSU, had participated in an education session and subsequently initiated family discussions overcoming existing cultural and information barriers.

The education sessions provided current comprehensive information about organ donation, highlighting the existence of a knowledge discrepancy among participants and their family members. The knowledge discrepancy according to the TMIM, created a degree of uncertainty which was more than participants desired. The Theory of Motivated Information Management suggests that the knowledge discrepancy then initiates a prolonged cascade of evaluations processes which originate from anxiety created by the uncertainty discrepancy. The participants in this study did not identify that the knowledge discrepancy created anxiety in them but instead identified a knowledge deficit as being the main inhibitor of the family discussion. This knowledge deficit was addressed within the education session and provided the participants with sufficient information to enable a family discussion to take place. The Theory of Motivated Information Management was initially incorporated within this study to assist with identifying the barriers that people encounter in initiating a family discussion about organ donation. It is possible that participants actually do participate in outcome assessments and efficacy assessments before making the decision to seek relative information from family members. These assessment processes did not appear apparent to the researcher in the focus group discussions.

The participants in this study instead appeared to initiate a more simplified lineal process in initiating family discussions. The lineal process is diagrammatically presented in figure 2

Figure 2: Family conversation model for Organ Donation – diagrammatically presented



Barriers overcome from the educational sessions included the knowledge deficit, hectic pace of life and age. The remaining barrier of geographical distribution of family members was not able to be assessed through this research project.

The findings from this study suggest that people are more likely to hold a conversation with their family when they have had an opportunity to be given accurate information about organ donation and have a physical opportunity to have that discussion with their family. A lack of information, which has been identified in previous studies ^(9, 10, 27), was a significant barrier inhibiting family discussions about organ donation wishes. While some people in this study had initiated conversations as a result of watching television programs such as 60 Minutes, or following viewing television advertisements which encourage family discussion, the majority of participants in this study, who had not been involved in an education session, had not held a family discussion. Providing an education session and the opportunity for people to ask questions about organ donation appears to provide participants with information and confidence to initiate family discussions about organ donation wishes.

Strengths and Limitations to the study

This study was exploratory in nature, incorporated a small sample size of predominantly female participants from a specific rural area within NSW. These factors therefore limit the generalisability of the results. The findings therefore may not represent the views of the larger population.

Two of the focus groups were provided with an education session prior to participating in the focus group discussion. The two remaining focus groups were not provided with an education session prior to participating in the study. This change in strategy took place due to saturation of themes, and concerns that facilitating additional focus groups in the initial format may not provide any additional information. A change in study design, to incorporate participants who had not previously been involved in an education session resulted in the identification of additional themes not previously identified. This change in strategy reduced the overall sample size again limiting the generalisability of results.

While every effort was made to ensure that the researcher was adequately equipped with skills to conduct a focus group, the researcher acknowledges the level of skill is that of a novice researcher and this may again influence the interpretation of the findings.

The strength of this research is the sound methodological approach, with early saturation of ideas. Additional strengths included age variation, (14 years to 80 years) and the incorporation of senior school children, participants with a trade qualifications, university qualifications, and retired seniors as this provides the broadest and most generalisable findings.

Conclusion

This study identified that barriers do exist which prevent rural families from having a conversation about their organ donation wishes. The barriers to family conversations identified in this study include a lack of information, the geographical distribution of rural family members, the hectic pace of family life, and age.

Educational sessions in this study were the catalyst that initiated family conversations about organ donation wishes, by providing participants with the knowledge and confidence to raise the subject within families even when it was known that organ donation was not supported, or where traditional cultural resistance existed. Family discussions were also able to be facilitated overcoming an identified barrier which was the hectic pace of family life as a result of being involved in the education session.

School children in this study embraced information about organ donation and subsequently initiated family discussions despite family structure or the busyness of family life. Some of the school children then extended the discussion outside of the family into social groups.

Recommendations

Engaging the community and providing current comprehensive information about organ donation is a vital strategy in increasing family discussions and organ donation rates in Australia. Community service groups such as Rotary and PROBUS and Lions clubs are keen to have guest speaker's talk to their members and it is relatively easy to engage these groups. It can be extremely challenging to engage wider community groups such as essential services, education groups and businesses.

School children were the strengths in facilitating family communication about organ donation wishes in this study. Children generally live within family environments which is conducive to talking about what was learnt or what happened at school that day. This study therefore supports the incorporation of age appropriate organ donation education into the school curriculum which will have a lasting effect in encouraging family discussions and changing the culture surrounding organ donation in Australia.

The geographical distribution of family members is a barrier which may only be partly addressed by education sessions, and may be subject to when the family next meet or communicate. Screening the DonateLife advertisements on television near traditional annual holiday times like Christmas when families are more likely to gather may assist in overcoming this barrier.

References

1. Bendorf A, Kerridge IH, Kelly PJ, Pussell B, Guasch X. Explaining failure through success: a critical analysis of reduction in road and stroke deaths as an explanation for Australia's low deceased organ donation rates. *Internal Medicine Journal*. 2012;42:866-73.
2. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors Influencing Families' consent for donation of solid organs for transplantation. *Journal American Medical Association*. 2001;286(No. 1):71- 7.
3. Callender CO, Washington AW. Organ/Tissue Donation the Problem! Education the Solution: A review. *Journal of the National Medical Association*.89(10):689 - 93.
4. Lynch SV, Balderson GA, editors. Australian and New Zealand Liver Transplant Registry Report 2010.
5. Mc Donald S, Hurst K, editors. Thirty Fourth Annual Report 2011.
6. DonateLife. National Reform Agenda n.d [cited 2012 30/08/2012]. Available from: www.donatelife.gov.au/the-authority/national-reform-agenda.
7. DonateLife. Facts & Statistics n.d. [cited 2012 30/08/2012]. Available from: <http://www.donatelife.gov.au/discover/facts-a-statistics>.
8. Volz Wenger A, Szucs TD. Predictors of family communication of one's organ donation intention in Switzerland. *International Journal Public Health*. 2010.
9. Waldrop DP, Tamburlin JA, Thompson SJ, Simon M. Life And Death Decisions: Using School-Based Health Education to Facilitate Family Discussion About Organ and Tissue Donation. *Death Studies*. 2004;28:643-57.
10. Hyde MK, White KM. Young Australian adults' knowledge and beliefs about organ donation. *Progress in Transplantation*. 2007;17(3):220-7.
11. Mc Donald DD, Ferreri R, Jin C, Mendez A, Smail Julie, Balcom P, Shoemaker S, Kamuzora PL, Durham R, Dibble J. Willingness to Communicate Organ Donation Intention. *Public Health Nursing*. 2007;24(2):151-9.
12. Smith SW, Kopfman JE, Massi Lindsey LL, Yoo J, Morrison K. Encouraging Family Discussion on the Decision to Donate Organs: The Role of the Willingness to Communicate Scale. *Health Communication*. 2004;16(3):333-46.
13. Sheehy E, Conrad S, Brigham L, Luskin R, Weber P, Eakin M, Schkade L, Hunsicker L. Estimating the Number of Potential Organ Donors in the United States. *New England Journal of Medicine*. 2003 (August 14, 2003):667-74.
14. Siminoff LA, Gordon N, Hewlett J, Arnold R. Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation. *Journal American Medical Association*. 2001;286(1):71-7. Epub July 4, 2001.
15. Rodrigue JR, Cornell DL, Howard RJ. Organ Donation Decisions: Comparison of Donor and Nondonor Families. *American Journal of Transplantation*. 2006;6:190-8.
16. Brashers DE, Goldsmith DJ, Hsieh E. Information Seeking and Avoiding in Health Contexts. *Human Communication Research*. 2002;28(2):258-71.
17. Koerner AF, Fitzpatrick MA. Toward a Theory of Family Communication. *Communication Theory*. 2002;12(1):70-91.
18. Afifi WA, Weiner JL. *Communication Theory* 2004.
19. Afifi WA, Weiner JL. Toward a Theory of Motivated Information Management. *Communication Theory*. 2004;14(May 2004):167 - 90.
20. Afifi WA, Morgan SE, Stephenson MT, Morse C, Harrison T, Reichert T, et al. Examining the decision to talk with family about organ donation: Applying the theory of motivated information management. *Communication Monographs*. 2006;73(No 2, June 2006):188-215.

21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32 -item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007;19(6):349-57.
22. Population Health Planning and Performance Directorate. North Coast Area Health Profile. North Coast Area Health Service, Lismore n.d. [30/04/2012]. Available from: <http://www.ncahs.nsw.gov.au/health-profile/>.
23. Kitto S, Chesters J, Grbich C. Quality in qualitative research Criteria for authors and assessors in the submission and assessment of qualitative research articles for *Medical Journal of Australia*. *Medical Journal Australia*. 2008;188(4):243-6.
24. Sydney TUO, (Research) DV-C. Guidelines: Snowballing - Active and Passive 2012 [cited 2012 30/04/2012]. Available from: http://sydney.edu.au/research_support/ethics/human/guidelines/snowballing.shtml.
25. Description STJ. Sterilization Technician Job Description n.d. [30/08/2012]. Available from: http://www.ehow.com/facts_5918164_sterilization-technician-job-description.html.
26. Inc UANRL. Welcome n.d. [30/08/2012]. Available from: <http://www.u3anriv.org.au/>.
27. Irving M, Tong A, Jan S, Cass A, Chadban S, Allen R, et al. Community Attitudes to Deceased Organ Donation:A Focus Group Study. *Transplantation*. 2012;93(10):1064-9.

Appendix A: Initial contact letter



**Subject line: Invitation to take part in a focus group discussion for the study
'Are there barriers to family communication about organ donation?'**

Dear

I would like to invite you to participate in a focus group discussion for the abovementioned study which I am conducting as part of the Clinical Education and Training Institute (CETI) scholarship. This research project has been approved by the NCAHS Human Research Ethics Committee.

My name is Mary Campbell and I am employed by Northern New South Wales Local Health District. My role is to provide education and promote discussion within the community about organ donation wishes.

The aim of this focus group discussion is to explore if there were difficulties encountered in having this conversation among family members. The focus group discussion will be recorded, then transcribed by me.

If you are interested in sharing your experience and thoughts with me, please read the attached Participant Information Statement. If you are still interested please complete the Participant Consent Form, including your name and contact number so that I can contact you with the date and time of the proposed focus group.

Please return the completed form to your group leader.

Thank you for reading this letter,

Mary Campbell
Clinical Nurse Specialist
Organ and Tissue Donation
NNSWLHD
Email: Mary.campbell@ncahs.health.nsw.gov.au
Telephone: 0421 612186

Version 1 29/06/2011

Appendix B: Participant information statement



Participant Information Statement

'BARRIERS TO FAMILY DISCUSSION ABOUT ORGAN DONATION WISHES'

1. What is the purpose of the project?

The purpose of this study is to identify if individuals encountered any difficulties in having a memorable discussion within their family or friendship group about their organ donation wishes. It will also ask participants if they can identify what types of cues if any assisted in initiating this conversation.

This study will hold focus group discussions (of approximately one hour duration) with up to 10 participants who will be invited to share their experience in relation to holding a memorable family discussion.

This study will include an anonymous brief questionnaire to identify participant's demographics. The questionnaire will be distributed and completed at the beginning of the focus group meeting.

2. Why have I been invited to participate in the study?

I am looking for people who have participated in an information session in the previous twelve months where attendees were provided with facts about organ donation in Australia, and subsequently encouraged to have a family discussion about their organ donation wishes, who are willing to discuss these conversations including factors which facilitated or hindered family discussion.

3. What if I don't want to take part in the study, or if I want to withdraw later?

Participation is entirely your choice. If you do not wish to participate you do not need to do anything. If you do wish to participate, complete the Participant Consent Form and return it to the collection point (group leader) and I will contact you to within seven (7) days to let you know the date and time.

If you wish to consider being involved in the focus group discussion, please contact Mary Campbell by phone on 0421612186 during working hours or e-mail mary.campbell@ncahs.health.nsw.gov.au within (7) seven days.

If you decide to participate, you may withdraw participation without giving a reason at any time, by signing and returning the '***If you wish to withdraw your consent at any time***' section in the Participation Consent Form. You will be provided with a copy of the Participant Consent form for this purpose should you require it.

4. What will participation involve?

Your Participation will involve filling a brief questionnaire and then participating in a recorded group discussion about your experience, which may take up to one hour depending on the group discussion. The interview will take place in your normal meeting place.

5. Will taking part in the study cost me anything and will I be paid?

Participation in the focus group is voluntary, and you will not incur any financial cost for your involvement.

You will not be paid for being involved in the study, however prior to the commencement of the focus group, a complimentary light refreshment will be provided.

6. How will my confidentiality be protected?

It is completely up to you if you want to be part of this study, and no one except my assistant and I will know that you have been included in the focus group discussion.

The information on the recorder will be transferred into a password protected electronic audio file on a secure drive after which the recorder will be wiped clean. The de-identified data will then be transcribed and placed into another folder on a secure drive. This will also be password protected. This transcribed file will be used for analysis. Following which the transcribed file will be destroyed following a 5 (five) year period, from the date of collection.

Anything said in the interviews will be totally de-identified (i.e. name, place and time of interview, and all experiences stated) before reporting so that any statements, ideas, or opinions will not be able to be tracked back to you. There will be no identification of the people on the transcription.

7. What happens with the results?

The results of this study will help us understand what factors help and hinder families in having memorable discussion about organ donation.

If appropriate, this information may provide valuable information which may help to support the way future advertising campaigns are run in prompting family discussions.

The results, as de-identified data will be written up as a report for the Clinical Education and Training Institute (CETI). I also expect to present the results at professional conference(s) and publication in an academic and/or professional journal may follow.

The de-identified results may also be presented within the Area Health District to interested parties.

8. What should I do if I would like further information regarding this study before I decide to participate?

Should you have any questions after reading this information, please contact me for further details.

Mary Campbell
Clinical Nurse Specialist, Organ and Tissue Donation
NNSW LHD
Phone: 0421612186 (Business Hours)
E-mail: mary.campbell@ncahs.health.nsw.gov.au

9. What should I do if I have a complaint or concerns about this project?

The NCAHS Human Research Ethics Committee has approved this research project. Any complaints or concerns about this research project may be made to the NCAHS Human Research Ethics Committee through the research Ethics Officer, quoting LNR - 012, as follows:

Research Ethics Officer
NCAHS Human Research Ethics Committee
PO Box 126
Port Macquarie NSW 2444
Tel: (02) 65882941
Fax: (02) 65882942
Email: EthicsNCAHS@ncahs.health.nsw.gov.au

Thank you for taking the time to read this participant information sheet.

Should you wish to participate in the study, please sign the attached Participant Consent form.



Participant Consent Form

I hereby consent to participate in a focus group discussion, about families discussing their organ donation, wishes which will be digitally recorded, and to complete an anonymous questionnaire at the beginning of the focus group.

I have read and understood the information in the Participant Information Sheet, which I have a copy of and understand that a copy of this consent form will be returned to me.

I also understand that the data I provide will remain de-identified as outlined in the Participant Information Sheet.

Should I wish to withdraw from the study at any time I understand I can do so without having to provide any explanation or reason.

Participant

Print Name: _____ Contact Number _____

Signature: _____ Date: _____

✂-----

If you wish to withdraw your consent at any time and for your information not to be used please sign below and mail to:

Mary Campbell
Clinical Nurse Specialist
The Tweed Heads Hospital
Powell St,
Tweed Heads

Please withdraw my data from the “family discussing their organ donation wishes” research.

Participant Name _____ *(please print)*

Signature: _____ Date: _____

Version 1 – 29/06/2011



Invitation to be part of a research focus group

Background:

In June 2011, I presented some background information on Organ Donation in Australia, and discussed the importance of having family discussions about your wishes.

I would now like to invite you to partake in a group discussion to identify if you were able to hold that discussion with your family. If you were not at the presentation you are most welcome to participate.

Date: 2nd November 2011

Time: 2.30 pm

Venue: Staff tea room, CSSU

Afternoon tea will be provided

If you are willing to participate would you please write you name below and I will distribute an information pack and consent form to you.

1 _____	8. _____
2 _____	9. _____
3 _____	10. _____
4 _____	
5 _____	
6 _____	
7 _____	

Many Thanks
Mary Campbell

Appendix E Southern Cross University flyer



NSW ORGAN AND TISSUE
DONATION SERVICE
NSW HEALTH



Health
Northern NSW
Local Health District

Organ Donation ~ Focus group discussion ~ Invitation

You are invited to participate in a focus group discussion on having family discussions about your organ donation wishes.

Date: February 2012

Time: To be advised

Venue: Southern Cross University –Tweed Heads campus

Morning Tea provided

If you would be willing to participate please write your name on the form below.

A participant information package will be provided prior to the focus group meeting.

In appreciation of your time a \$20.00 gift voucher will be provided to participants.

If you are willing to participate would you please write you name below and I will distribute an information pack and consent form to you.

- 1 _____
- 2 _____
- 3 _____
- 4 _____
- 5 _____
- 6 _____
- 7 _____
- 8 _____
- 9 _____
- 10 _____

Mary Campbell ~ 0421612186

Appendix F University of the Third Age flyer



NSW ORGAN AND TISSUE
DONATION SERVICE
NSW HEALTH



Health
Northern NSW
Local Health District

Organ Donation ~ Focus group discussion ~ Invitation

You are invited to participate in a focus group discussion on having family discussions about your organ donation wishes.

Date: 9th February 2012

Time: 10am - 1130

Venue: Lismore Workers Club

Morning Tea provided

If you are willing to participate would you please write you name below and I will distribute an information pack and consent form to you.

- 1 _____
- 2 _____
- 3 _____
- 4 _____
- 5 _____
- 6 _____
- 7 _____
- 8 _____
- 9 _____
- 11 _____
- 12 _____
- 13 _____
- 14 _____
- 15 _____

Mary Campbell ~ 0421612186