# **Chapter 8**

# The substantive theory

# Introduction

revious chapters discussed the open and selective coding stages of the constant comparative method of analysis. The movement from the first stage of analysis to the second, third and fourth stages is not linear and the researcher is required to move back and forth from one stage to another as they constantly compare the data during each phase of the process. It is also during the open and selective coding phases that the properties of the categories and the links between the categories and the core category may begin to emerge from the data. This chapter addresses stage two - the integration of categories and their properties, stage three - delimiting the theory and stage four - writing the theory.

Stage two is the phase of coding in which the properties and connections between the categories and the core category are integrated (Glaser & Strauss Integrating 1967). This is achieved in two ways: firstly, the memos written by the researcher their properties throughout the study are theoretically sorted; and secondly, questions about the categories are asked. This is facilitated by using theoretical codes, which assist in the identification of the properties and links between categories and the core category (Chenitz & Swanson 1986; Glaser & Strauss 1967). This process also requires that incidents in the data be compared with each other as well as comparing them to the properties of the categories as they emerge (Glaser & Strauss 1967).

categories &

The next step in the constant comparative analysis cycle is stage three - the This is achieved at both the theory Delimiting the theory delimiting of the emergent theory. development and category levels (Glaser & Strauss 1967). As the theory emerges the need for major modifications become less as the categories and their properties become saturated. At the category level the theory is delimited by removing the non-relevant properties (Glaser & Strauss 1967). processes lead to a reduction in the data resulting in a theory that has 'a smaller set of higher level concepts' (Glaser & Strauss 1967, p. 110).

The final stage of the constant comparative analysis cycle is stage four - writing Writing the the theory (Glaser & Strauss 1967). At this point all the data has been coded,

categories identified, the properties and the links between categories established and the emerging theory has been delimited. It is the phase of the research when the substantive theory is articulated.

This final chapter then examines the implications of the findings in relation to transplant coordinators and their role. Opportunities for the dissemination of the findings are also explored. The chapter concludes with the limitations of the study and a brief overview of the areas relating to transplant coordinators and their practice, which may benefit from further research.

# Integrating categories and their properties

During the open and selective coding of the focus group interviews, Delphi survey questionnaires and relevant literature, the researcher also looked for the emerging properties of and links between the categories and the core category. At this stage the focus was on integrating the four categories that had emerged from the data together with their properties. The categories were:

- KNOWLEDGE AND EXPERIENCE
- THE ROLE
- OUTCOMES
- RELATIONSHIPS the potential core category.

To achieve this, theoretical codes were used to generate a series of questions of each of the categories to identify properties and links between them and the core category. Glaser (1978) states that:

... theoretical codes conceptualise how the substantive codes may relate to each other as hypotheses to be integrated into a theory. They, like substantive codes, are emergent; they weave the fractured story back together again (Glaser 1978, p. 72).

Chenitz and Swanson (1986, p. 125) also support this notion, stating that theoretical coding families allow for the organisation of the categories, clarification of each category in relation to the others and the identification of the links between the categories and the core category. The links between each of the categories and the core category enable the generation of the substantive theory (Chenitz & Swanson 1986).

A number of theoretical coding families assist in the integration of categories and the researcher must choose the most appropriate for their research (Glaser 1978,

pp. 72-82). Furthermore, Glaser (1978) states that the theoretical codes are not mutually exclusive and in some cases may overlap considerably. Hence the researcher may begin with one or two of the theoretical codes and then move to another coding family or families as new ideas develop and the substantive theory emerges. To ensure that the most appropriate coding families were selected the researcher reviewed all the theoretical coding families. continued throughout the analysis to ensure potentially helpful codes were not overlooked.

#### Theoretical codes

Several theoretical coding families were used in this study. The first of these was 'The Six Cs: Causes, Contexts, Contingencies, Consequences, Covariances and The Six Cs Conditions' (Glaser 1978, p. 74). Glaser (1978, p. 74) states that 'most studies fit into either a causal model, a consequence model or a condition model'. The Six Cs coding family is the 'bread and butter' theoretical code of sociology and the one that is recommended for beginning researchers (Chenitz & Swanson 1986, pp. 125-126; Glaser 1978, p. 74).

The Six Cs coding family, like others, is used to assist in identification of the theoretical connectors or links between the categories and the core category. To do this a series of questions are asked when analysing the data in each of the categories. Chenitz and Swanson (1986, p. 126) and Glaser and Strauss (1967,

- Is this category a condition of some other category?
- Is it a cause, context or a contingency of another category?
- Is it a consequence of another category?
- Does this category co-vary with other categories?
- Is this a strategy?

p. 74) give examples of such:

Following initial examination of the properties and links between the categories Interactive, and the core category using the Six Cs coding family, it became evident that Cutting Point other coding families could also facilitate this process. The Interactive, Process and Cutting Point coding families were also used to identify the links between categories and the core category (Glaser 1978, pp. 74-76). Table 8.1 summarises the theoretical coding families and highlights the descriptive codes used in this study. The study memos were also theoretically sorted and used to

coding families

coding family

identify the properties of each of the categories and the links between them, and with, the core category.

Theoretical coding families	Descriptive codes	
The Six Cs coding family  This is the first general code to use when coding data	<ul> <li>Causes</li> <li>Contexts</li> <li>Contingencies</li> <li>Consequences</li> <li>Covariances</li> <li>Conditions</li> </ul>	
Interactive coding family  This code captures the interacting patterns of two or more variables	<ul> <li>Mutual effects</li> <li>Reciprocity</li> <li>Mutual trajectory</li> <li>Mutual dependency</li> <li>Independence</li> <li>Interaction of effects</li> <li>Covariance</li> </ul>	
Process family  This code must have at least two or more stages	<ul> <li>Stages</li> <li>Staging</li> <li>Phasings</li> <li>Progressions</li> <li>Passages</li> <li>Gradations</li> <li>Transitions</li> <li>Steps</li> <li>Ranks</li> <li>Careers</li> <li>Orderings</li> <li>Trajectories</li> <li>Chains</li> <li>Sequencings</li> <li>Temporaling</li> <li>Shaping</li> <li>Cycling</li> </ul>	
Cutting point family  This code indicates where differences occur which have differential effects	<ul> <li>Boundary</li> <li>Critical juncture</li> <li>Cutting point</li> <li>Turning point</li> <li>Breaking point</li> <li>Benchmark</li> <li>Division</li> <li>Cleavage</li> <li>Scales</li> <li>In-out</li> <li>Intra-extra</li> <li>Tolerance levels</li> <li>Dichotomy</li> <li>Trichotomy</li> <li>Polychotomy</li> <li>Deviance and point of no return</li> </ul>	

Table 8.1: Diagram showing the coding families used in this study

### Theoretical sorting of the research memos

To assist with the emergence of the substantive theory the theoretical memos are sorted. Glaser (1978) states that:

Memos are the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding (Glaser 1978, p. 83).

To support this sorting, eleven analytic rules are used to assist and guide the process of theory generation and keep it 'on track' (Glaser 1978, p. 121). Some rules are used throughout the entire analysis whilst others are only used to identify the properties of and the links between the categories and the core category. Following is an overview of the rules for memo sorting (Glaser 1978, pp. 121-127):

The beginning of the sorting process: Sorting can begin at any point within the collection of theoretical memos – not necessarily with the first memo written.

Sorting in relation to the core variable or Basic Social Process (BSP): Sorting of the memos is guided by their relationship to the core variable or BSP. Glaser (1978, p. 121) suggests that 'if a concept is not related to the core variable or a property of it in some way, then the concept is left out of the theory, since it obviously has no use in it'. This focuses the analysis process and assists in delimiting the emergent theory.

Competing core variables: In the event of two potential emergent core variables the researcher must promote or demote one of them. The goal of theory development is not to present all theoretical perspectives or explain every variation that may emerge from the research data. The demoted variable becomes a category like the others, which subsequently relate to the central core variable for the purposes of theory generation and write up.

Adding memos: As the theoretical sorting of memos relating to the core category, categories, properties and links between each of the variables progresses there may be new ideas that emerge which need to be documented into memos. Glaser (1978, p. 121) states that it is important to stop the sorting process in order to record the new ideas as they emerge.

Carrying memos forward: It is important to continually memo throughout the course of the study and carry the memos forward to each of the stages in the constant comparative analysis. The cyclical nature of the analytical process may

also necessitate the researcher moving the memos back and forth in a non-linear fashion to enable the substantive theory to emerge.

Integrating ideas so they fit into the emerging theory: 'All ideas must fit in somewhere in the outline, or the integration must be changed or modified' (Glaser 1978, p. 123). It is the researcher's exploration of the underlying patterns emerging from the data that enable a theory that is integrated and has fit.

**The levels of sorting:** To fit codes and categories within the emergent theory, the sorting of memos must take place at the descriptive and conceptual levels.

Problems with memo integration: The process of memo integration may sometimes be difficult as it is not always clear where an idea, which is documented in a memo, should be placed in the emergent theory. Glaser (1978, p. 124) makes the analogy that integrative sorting is like completing a jigsaw puzzle; it may initially be unclear where an idea fits but as the picture evolves the placement of pieces becomes clear.

**The cessation of sorting:** Glaser (1978, p. 124) offers several reasons for ceasing the memo sorting process, the most significant of which are category saturation and/or theoretical completeness.

The actual process of sorting: This refers to the actual mechanics of how memos are sorted and processed. For example in this study the memos were copied, the original memos were kept as the master copy and the photocopied memos were cut into individual memos and placed in piles relating to each of the categories and the core category. The process of sorting may differ between studies, depending on the researcher's personal style and the nature of the data collection method or methods.

**Pacing the theoretical process:** This refers to the balance between being engrossed in memo sorting and allowing enough 'thinking time' to enable ideas to develop as the sorting process evolves.

# Stage two - The development of the emergent theory

In this section the development of the emergent theory is presented. The process of theory extrapolation was facilitated in two ways – by using the theoretical coding families as discussed above together with the integration of ideas contained in the memos. This assisted in identification of the category properties and links between each of the categories and the core category. It

should be highlighted that the properties and their characteristics were not always exclusive to a single category - there was repetition with some properties being described in one or more of the categories. This is unsurprising at this stage of analysis as the categories are interrelated. Through the process of examination and reduction, they are being woven together to form an integrated substantive theory. Appendix 38 shows the theoretical codes that best describe each category and provides an overview of the main properties and their characteristics in relation to each of the categories that emerged in the study.

## Category - knowledge and experience

The category KNOWLEDGE AND EXPERIENCE is a condition of the category Is this category OUTCOMES. Some participants, particularly recipient coordinators, indicated some other that there were instances where incorrect information had been given to them or inappropriate referrals made. This led to actual or potentially poor OUTCOMES, for the transplanted patients and donor families as well as financial, emotional and time costs:

a condition of category?

... we've travelled hundreds of miles to get there and find ... emphysematic changes and they offer me lungs ... and that is just one of the incidents ... but there are many and that was a very big ... waste of money. I flew planes everywhere ... it was just a nightmare ... the CT scan was just so obvious ... no way could you give the lungs away (RFG, p. 55, L. 20-23; p. 56, L. 1-4; L. 14-15).

... I got an offer [from a donor coordinator] of a heart from a woman that had had an AMI [acute myocardial infarction] ... the person relating the information to me was not a nurse ... it wasted a hell of a lot of time and effort ... (RFG, p. 56, L. 23-24; p. 57, L1-2).

KNOWLEDGE AND EXPERIENCE may also be a condition of the categories THE ROLE and RELATIONSHIPS. Without the appropriate KNOWLEDGE AND EXPERIENCE in this case, knowledge of the political arena and the broader infrastructure in which organ donation and transplantation takes place, a number of coordinators felt it would be difficult to perform THE ROLE adequately:

Many coordinators take a long time to grasp their role and their state's infrastructure and don't have an appreciation of the political environment in which they work (DS2, p. 6, L. 4-5).

Coordinators depend on information given to them by their colleagues as well as other health professionals. Obviously, they are not always in a position to be on site, as referrals are made throughout Australia and New Zealand. Trusting others, however, is not always easy or indeed wise if there are doubts about knowledge, experience and/or expertise:

... you're trusting somebody else ... especially for the transplants once you're in you've gone ... you know you've made your decision and you're moving off ... (RFG, p. 61, L. 2-4; L. 12-13).

Therefore KNOWLEDGE AND EXPERIENCE is a prerequisite on which the other To perform THE ROLE, facilitate OUTCOMES and categories are reliant. engage in meaningful interaction with others in the field the coordinators need a certain level of KNOWLEDGE AND EXPERIENCE.

KNOWLEDGE AND EXPERIENCE is possibly a cause of the category is it a cause of another OUTCOMES. With respect to grounded theory, the causal theoretical code is a category? '... sub-family called: sources, reasons, explanations, accountings or anticipated Here, cause was interchanged with Reasons or consequences' (Glaser 1978, p. 74). anticipated AND consequences KNOWLEDGE anticipated consequences, thus reasons or EXPERIENCE could be one of the reasons or anticipated consequences for OUTCOMES. In the following example KNOWLEDGE AND EXPERIENCE is seen to be the reason for efficient transplant programs, generating a positive OUTCOME:

These are specialist areas requiring a high level of knowledge in order to be able to coordinate an efficient transplant program (DS1, p. 40, L. 30-31).

As shown in previous examples an anticipated consequence of KNOWLEDGE AND EXPERIENCE is that correct information will be forwarded.

This category may impact on OUTCOMES whereby both positive and negative ones may be directly linked to levels of KNOWLEDGE AND EXPERIENCE. This category too, may influence the RELATIONSHIPS transplant coordinators engage in or are exposed to.

KNOWLEDGE AND EXPERIENCE may be contingent on the core category Is it a RELATIONSHIPS. To achieve a level of KNOWLEDGE AND EXPERIENCE another coordinators often rely on their colleagues:

contingency of category?

I needed that person [the other coordinator] to help me receive my training ... until I had enough experience ... to do it by myself (DFG, p. 43, L. 31; p. 44, L. 1-3).

'On the job' experience is important as long as initially supervised and then as [one becomes] more experienced a resource person [is] available at all times (DS1, p. 45, L. 5-6).

The category KNOWLEDGE AND EXPERIENCE is also a consequence of the Is it a consequence of other categories. THE ROLE provides opportunities for learning and skill another category?

development. OUTCOMES enable feedback, leading to evaluation of practice and further understanding, knowledge and changes in procedures and protocols if necessary. RELATIONSHIPS are the catalyst for coordinators' learning and experiences within the field.

KNOWLEDGE AND EXPERIENCE may co-vary with the other categories. Does this KNOWLEDGE AND EXPERIENCE varies depending on the availability of organ vary with other categories? donors, with low organ donation rates limiting opportunities for learning and the attainment of skills. This also dictates how many transplants are performed thus impacting on the recipient coordinators' potential for gaining KNOWLEDGE AND EXPERIENCE. Hence THE ROLE impacts on the coordinators' development and therefore **co-varies** with this category.

For example the number of organ donors in the Northern Territory (NT) is significantly less in comparison to New South Wales (NSW). A recently appointed coordinator in the NT would take significantly longer to gain a level of KNOWLEDGE AND EXPERIENCE when compared to a new recruit practicing in NSW. The following comment highlights the difficulties encountered in gaining the practical KNOWLEDGE AND EXPERIENCE required to perform THE ROLE when the organ donation rates are low:

When I first started ... there was an all time low with organ donors ... it was three months ... before a first organ donor event took place and in ... almost seven months there were three organ donors in total (DFG, p. 40, L. 16-20).

Similarly, KNOWLEDGE AND EXPERIENCE may vary with the level and type of support received from colleagues and other health care professionals. Thus this category also co-varies with the core category RELATIONSHIPS. The following example demonstrates the dependency coordinators have on one another to gain the required KNOWLEDGE AND EXPERIENCE. This situation can be exacerbated when RELATIONSHIPS are poor. It is more problematic if the coordinator who is relied on for education is the only one available:

... not having ... any health background created a situation where I needed my colleague ... I needed that person to help me receive my training ... So I invested a lot of time and energy into that relationship to ensure that it would be positive. ... that individual already felt quite negative because of past history ... so I didn't have a supportive relationship with my colleague (DFG, p. 43, L. 29-31; p. 44, L. 3-8).

KNOWLEDGE AND EXPERIENCE could also be seen as a strategy for gaining Is this a strategy? recognition and respect within the field:

... when you've worked with these people for a long time and when new doctors come ... you train them ... you take them on donor runs and tell them how to do it ... they come to you and ask you, the nurses come to you and ask you ... you have this huge body of information that's just there all the time and you know it's increasing all the time (RFG, p. 19, L. 17-26).

The category may also be a **strategy** to achieve better OUTCOMES - the more experienced and knowledgeable the coordinator is, the more likely the OUTCOMES will be positive as suggested:

... it is a highly specialised role that incorporates many facets and expertise. For example - the clinical and theoretical knowledge that is required, but also the ability ... to deal with the families of donor patients takes a lot of specialised expertise and is the difference between positive and negative outcomes (DS2, p. 29, L. 8-11).

## The Process theoretical coding family

When the Process family was used to ask questions of the data it appeared to \*Process family\* also have explanatory value in regard to this category. The attainment of KNOWLEDGE AND EXPERIENCE is a process. This process is also influenced by the coordinators' educational background, prior employment experience, the number of organ donation or transplantation processes they have been involved in, the availability of peer support and the coordinators' access to courses/educational opportunities to facilitate advanced training and networking. KNOWLEDGE AND EXPERIENCE is therefore obtained in stages, phases or steps:

Within a supportive team [there is] the opportunity to build skills and learn new things and have the chance to be responsible for my projects/activities but report back to the team for feedback (DS1, p. 31, L. 18-20).

Other properties that emerged from the data were that KNOWLEDGE AND EXPERIENCE is about obtaining a level of competence, learning the job, taking responsibility, continuing education, providing a quality service or best practice, advancement, improvement, building on prior knowledge and expertise and who should perform the role. Data, especially from the recipient coordinators, suggested that coordinators should have a nursing qualification. Most however, believed a specific transplant coordination university qualification was unnecessary although there was support for professional and continuing education in the form of credentialing.

# Category – the role

It appears that THE ROLE is a condition of the category OUTCOMES and the Is this category core category RELATIONSHIPS:

a condition of some other category?

You are expected to have a huge range of skills, be able to work long hours and always be available. ... Very few people understand the role, if they have not done it. You are all things to all people - supporter to the family, the staff (ICU & theatre staff) - technical expert in the role offering organs, decision making in terms of organ suitability, timing, etc. Responsible for the recipients - for example getting organs to the right place at the right time, responsibility for ensuring recipient units have accurate information so they can make reasonable decisions on behalf of the recipients (DS2, p. 29, L. 28-33; p. 30, L. 1-2).

To generate satisfactory OUTCOMES for donor families and recipients, coordinators in terms of job satisfaction, advancement and contributions to the field, there needs to be a role - an environment, within which these OUTCOMES can take place. THE ROLE encompasses the socio-cultural, political-economic, medico-legal, physical and/or the psychological environments and it is within this that RELATIONSHIPS are formed, developed and maintained:

The rewards come from the close intense relationships formed with donor families and colleagues (DFG, p. 1A).

I like seeing them survive. I like seeing them wander out the door and send me a card or ring me up and give me cheek ... (RFG, p. 79, L. 1-4).

THE ROLE is also a condition of the category KNOWLEDGE AND **EXPERIENCE**:

... I believe my vast case experience, greater than three hundred cases made me a more caring and knowledgeable donor transplant coordinator (DS1, p. 55, L. 9-10).

THE ROLE may also be a source or anticipated consequence of the Is it a source or categories KNOWLEDGE AND EXPERIENCE, OUTCOMES and the core consequence of category RELATIONSHIPS. THE ROLE requires the making of many decisions category? and in doing so the coordinator is a source of knowledge to the patient and their family:

anticipated another

There is no one else with [the] essential knowledge to provide education and support for both family and patient. Minimal knowledge with medical staff therefore a lot of decision making falls back to [the] coordinator in recipient care (DS2, p. 28, L. 2-4).

THE ROLE is at times highly stressful. If coordinators do not have support and a healthy balance between employment and their private lives the anticipated consequences are that THE ROLE can significantly contribute to negative OUTCOMES for them:

Over the years I've seen this job destroy the health and wellbeing of many coordinators, particularly donor coordinators. They quietly drop off the tree and no one notices because no one has stood up and shouted the plight of coordinators ... (DS2, p. 113, L. 28-30).

The following highlights the compelling nature of THE ROLE and identifies how it can be a **source** of complex and significant RELATIONSHIPS:

I think that was one of the best things about it [the role], you actually could get things done you could see the process through from beginning to end, you had a sense of closure, you could feel good about the fact that you had seen that family through that and that they had been able to stay in contact with you and...all the organs went to the right places and you [laughter] know the hospital staff...felt good about it and you'd had a chance to go and see them in the weeks and months after the retrieval ... (DFG, p. 12, L. 8-16).

The following examples also identify THE ROLE as the context in which many OUTCOMES are experienced and achieved. OUTCOMES for coordinators are not always pleasant and/or satisfactory and work stresses can encroach on their private lives. The second example demonstrates the contextual link between THE ROLE and the clients' OUTCOMES:

Family members are woken from sleep in the middle of the night. They and you suffer from sleep deprivation and all its consequences. No regular roster makes it extremely difficult to plan ahead or do any regular activity to relax and try to care for yourself. Long weekends are difficult to take and transplant coordination is an area where 'down time' is absolutely essential for mental and physical health (DS1, p. 13, L. 29-33).

... highly stressful approaching families of love ones. But very rewarding when you hear of the successes (DS1, p. 28, L. 8-9).

THE ROLE is also contingent on KNOWLEDGE AND EXPERIENCE, Is it a OUTCOMES AND RELATIONSHIPS. The example demonstrates that making a another difference to donor families and recipients is important to this coordinator and it is her reason for remaining in the position:

contingency of category?

I believe most coordinators believe that they make a difference to both donor families and transplant recipients. Otherwise they would not put up with the appalling 19th century conditions of the job (DS2, p. 36, L. 15-17).

Other properties and characteristics that contribute to and explain THE ROLE include: the work environment as one that is political, bureaucratic, involving significant legal issues and financial constraints. It also has public and personal significance and some cultural diversity. Conditions identified, as having a negative impact on coordinators were excessive workloads, unpredictable nature of the job, on call work, professional isolation, occupational health and safety issues, physiological and psychological stressors, burnout and attrition rates and effects on personal and/or family life.

THE ROLE attributes also have a significant influence on transplant coordinators. These include advocacy, autonomy, challenges, credibility, leadership, power, respect, responsibility, trust, uniqueness of THE ROLE and the intimacy of the job. Most coordinators also describe the intrinsic and extrinsic rewards they experience in THE ROLE. Extrinsic factors such as flexibility, meeting a variety of people and the challenges of the coordinators' position were positive attributes. The intrinsic factors such as intimacy of the job, connection with people and making a difference were some examples of the personal rewards coordinators experience.

There were however, two principle issues in THE ROLE. One is related to the Intimacy of the intimacy of the job - a factor that attracts a number of coordinators to THE ROLE and is the main reason they stay in the profession. For some, however, the intimacy of the job became the most negative and devastating:

I miss the ... intense intimacy that can exist in those situations but that's the very same factor that actually makes me grateful that I'm not there anymore because it [the job] can be so taxing (DFG, p. 14, L. 10-12; L. 16-17; L. 21).

... intimacy is certainly ... a real attraction to the job but something that can destroy you at the end. I mean the job, at the end I think ... does ... take ... literally your soul away ... (DFG, p. 15, L. 1-3; L. 6-7).

In retrospect, I resent the intrusion of this role on my personal life. I feel it contributed to my marriage breakdown (DS1, p. 14, L. 13-14).

intense and intimate connection coordinators feel with families/recipients attracts them to the position. This connection allows them to make a difference and contribute to something that is seen by them as unique, and miraculous. However, they are giving an enormous amount to others with little or no support offered to them:

... there should be the opportunity for formal debriefing in the workplace ... if there is any 'weakness' shown it seems that one is punished for it. Showing emotion or sharing feelings is absolutely frowned upon in the workplace. I think this leads to depression and anxiety (DS1, p. 2, L. 15-18).

THE ROLE attracts individuals with a desire to be in a nurturing/caring profession. Those who aspire to a professional position enabling autonomy and independent thinking, were also drawn to the transplant coordination role:

The kinds of people who do the job well are lateral thinkers and independent workers. Put a straight jacket on them and you'll get someone who ought to be in a mental institution (DS1, p. 58, L. 16-18).

There was a further focus on the altruistic nature of the coordinators' work with many stating they are in THE ROLE to make a difference and to help save and/or improve the quality of the lives of others. The reasons why individuals seek careers in helping professions have long been the subject of much debate and beyond the scope of this thesis. However, coordinators are essentially in their positions to earn a living and for their own professional and personal reasons. Very few endeavours are purely of an altruistic nature and transplant coordination is no exception.

The other issues in relation to THE ROLE were the views of the study cohort Autonomy or regarding autonomy and/or professional isolation. Statements included in the isolation first Delphi survey questionnaire explored these issues. Almost 60% of participants experienced professional isolation and over ninety per cent felt there was considerable autonomy in THE ROLE. Professional isolation was reexplored in the second survey and half of the cohort reported that they did indeed experience this.

professional

Coordinators felt professionally isolated due to being a sole practitioner, geographical isolation, non-supportive transplant coordinator colleagues and/or managers, lack of acknowledgement and/or understanding from other health care professionals and hospital administrators, excessive workloads, time constraints and minimal opportunities for networking:

People don't understand the recipient coordinator's role / work independently / job description differs to other nurse consultants (DS1, p. 20, L. 9-10).

Even though there are nine more of me in my state, I am still the only one in my health area. It can be lonely (DS1, p. 20, L. 14-15).

Thus whilst the position provides considerable autonomy for some coordinators, which is seen as a very positive aspect of THE ROLE, for others the level of autonomy often leads to professional isolation. Although autonomy and professional isolation may be two different entities they can also be linked. This contributes to a significant number of these health care providers feeling

professionally isolated due to the minimal contact they have with colleagues and other health professionals.

This category is best described by the term context and contingency from the Six Cs coding family. THE ROLE is about the environment, the physical Six Cs Familyenvironment - where interactions are taking place for example in a private area or contingency in a public domain, conditions - aspects of THE ROLE that affect the transplant coordinators, for example excessive workloads, on call work and unpredictable hours. Finally, THE ROLE attributes - as aspects of the position that attract coordinators in the first instance and may be the reasons why they continue to practice in spite of the less favourable features of the profession. Furthermore, THE ROLE is contingent on the other categories for its existence as without the other categories the transplant coordinator positions would be obsolete.

### Category – outcomes

This category is a condition of THE ROLE and RELATIONSHIPS. Again there is this category is considerable overlap between the categories. The first comment indicates that some other a positive OUTCOME makes it all worthwhile:

category?

No matter how much 'grief' is received by the coordinator during the transplant process it is very rewarding to see a patient successfully transplanted and returning to daily life (DS2, p. 36, L. 21-22).

The second example expresses a similar sentiment whereby both types of coordinators believe that they can have a positive impact and make a difference to donor families and recipients respectively:

... most coordinators believe that they make a difference to both donor families and transplant recipients (DS2, p. 36, L. 14-15).

Positive OUTCOMES are important in terms of job satisfaction and intrinsic rewards for the coordinators in relation to their role and the RELATIONSHIPS they engage in. A motivating factor for coordinators is their desire to make a positive difference for their clients. For donor coordinators this means caring for the donor families and accommodating their wishes where possible. recipient coordinators it means successful transplants for their patients.

Without positive Is this category OUTCOMES may be a source of RELATIONSHIPS. OUTCOMES in terms of organ availability, of families wishing to help others another through the donation of their deceased relatives' organs, RELATIONSHIPS would not be possible:

a source of

I find the intimacy that comes when a family lets you in. [lets you] share their love and sadness for their loved one, a privilege (DS2, p. 37, L. 14-15).

OUTCOMES as a source of RELATIONSHIPS are particularly evident with regard to recipients. Without a transplant many of these patients would die thus ending the potential for ongoing RELATIONSHIPS with these clients. Similarly, with no positive OUTCOMES in terms of organ donations, there would be no **RELATIONSHIPS** donor families. with Coordinators' professional RELATIONSHIPS with colleagues and other health care providers are also enhanced and developed if there are positive OUTCOMES within these interactions.

OUTCOMES might also be a consequence of the categories KNOWLEDGE Is it a In the following another AND EXPERIENCE, THE ROLE and RELATIONSHIPS. example the coordinator cites the recipient's positive outcome following transplant surgery as a rewarding aspect of THE ROLE:

consequence of category?

As a recipient coordinator, the opportunity to see a recipient regain a 'normal' life and be part of their recovery is definitely a reward (DS2, p. 36, L. 26-27).

Also demonstrated is the link between THE ROLE, RELATIONSHIPS and OUTCOMES, which can be positive, negative or a combination of the two:

When things go well and the families are happy you feel quite pleased with yourself. When things go badly like family dynamics you think of the recipient and still feel you're a part of something pretty amazing (DS1, p. 29, L. 2-4).

The final comment recognises the potential for poor OUTCOMES without the appropriate level of knowledge:

Without a high level of knowledge the information we give the community and support to donor families may be inadequate (DS1, p. 40, L. 25-26).

It is difficult to identify if the categories KNOWLEDGE AND EXPERIENCE, THE ROLE and RELATIONSHIPS always lead to the category OUTCOMES, or if there are instances when OUTCOMES facilitate the other categories. example the attainment of KNOWLEDGE AND EXPERIENCE through feedback mechanisms, THE ROLE in terms of the positive role attributes which may dictate the level of job satisfaction coordinators experience and RELATIONSHIPS in that OUTCOMES enable an ongoing connection with donor families and/or recipients. As with the 'chicken and egg' debates, the process appears to be circular with no clearly discernable start or end point.

category cocategories?

Data evidence suggests that the category OUTCOMES does co-vary with the Does this other categories that emerged in the study. The following example reiterates the vary with other importance of KNOWLEDGE AND EXPERIENCE in achieving a better understanding of the organ donation and transplantation process, thus ensuring better OUTCOMES for all involved:

... background knowledge in organ donation and transplantation enables a better understanding of the process (DS1, p. 40, L. 25-26).

The second example provides an explanation of how this category co-varies with THE ROLE in relation to the OUTCOMES coordinators experience. It highlights the fact that their role is at times unappreciated and OUTCOMES can be poor for coordinators in terms of their mental and physical health:

Most people think they can do it [the transplant coordinators job] until they try it. Usually they have no idea of what's involved - the level and breadth of skills, the emotions, the sleep deprivation, the stress levels, the thanklessness, the worry that everything will get to where its supposed to go and get there on time, being every one's 'kicking ball'. No one can tell you about this job you have to do it! You also need lots of life experience to do it well! (DS1, p. 44, L. 29-34).

The final comment establishes the co-variability between the categories OUTCOMES and RELATIONSHIPS whereby RELATIONSHIPS between medical staff and transplant coordinators are important for a positive OUTCOME in the organ donation process:

If a medical staff [member] is being uncooperative re availability, timing, regulations about donor availability etc. it makes the coordinator's role very difficult (DS2, p. 61, L. 18-19).

As well as striving to achieve positive OUTCOMES for their client groups, coordinators want to improve OUTCOMES for themselves. Suggestions included improved work conditions, appropriate acknowledgement and some form of career structure or a system that enables promotional avenues. OUTCOMES can be positive or negative. The facilitation of OUTCOMES was also seen as work in progress, going the extra mile, a source of job satisfaction, making a difference and turning a tragedy into something positive.

OUTCOMES also referred to the professional and personal needs of coordinators including gaining consensus on work practices, working as a team, job satisfaction, improved work conditions, more input into decision making processes, improved support systems, a better balance between work and private lives and recognition from others in the field.

The Cutting Point Family was also used to further explore the category The Cutting OUTCOMES. This highlights that there are critical junctures, turning and breaking points together with points of no return, which are apparent in the category OUTCOMES. For example in the organ donation and transplantation process there are critical junctures, which are clearly evident and are seen as points of no return as demonstrated:

... you've made your decision and you're moving off ... obviously right at cross clamp we still have time to say no let's pull out but that's our last opportunity (RFG, p. 61, L. 12 –13; L. 17-18).

This coding family also enabled the exploration of dichotomies within the Organ donation and transplantation are two parts of one whole. Although they fit together and are often reported in the literature, media and by those in the industry as such, these aspects are like 'two sides of the one coin' linked but separate. Although these facets of practice are independent of each other, they are also completely reliant on each other. With no organ donors there are no transplantations and with no potential recipients (ie. if scientists were able to clone organs), there would be no need for organ donors. Thus both aspects of the process are significant in terms of OUTCOMES for client groups, transplant coordinators and others in the field.

In a recently published article by Blumenthal (2007) regarding the experience of being a donation coordinator in the USA, she identified from her study cohort of 21, which included 16 current donor coordinators and 5 former donor coordinators, a number of issues affecting donor coordinators, supporting the findings of this study. These included the belief that the role of the donor coordinator is unique, complex and carries with it considerable responsibility. The desire to make a difference by saving or improving the lives of others was also offered as a reason for continuing in what is a demanding and challenging profession. Also attracting them to the position was the level of autonomy, variety and the inherent challenges involved in the role.

Other factors affecting the working lives of these health care providers, which were similar to those that emerged in the current study, were their feelings of professional isolation and a belief that only those with transplant coordination experience realistically understand the role. Blumenthal (2007, p. 12) discusses 'the power of relationships' and the connection these coordinators feel with the She also highlights a number of difficulties experienced by donor families. transplant coordinators including sleep deprivation, work demands, psychological stresses, the precarious balance between professional and personal lives and the ethical dilemmas organ donor coordinators experience in regard to organ donation being run as businesses, all of which emerged in this study.

As Blumenthal's article was published in March 2007 it has not been included in the literature review of this thesis but is acknowledged here with respect to the contribution it makes to transplant coordinators and their practice. It complements, in part, the findings of this research. It is noted that whilst the article presents a credible account of the working lives of these health professionals, Blumenthal's (2007) study is reflective of the more positive aspects of the role. This may be due to the fact that Blumenthal (2007) is an outsider in the field 'looking in' and as such coordinators are keen to reflect the positive and the 'more highly valued' aspects of their role.

The current research, which also addresses some of the more difficult and less appealing aspects of the role, may be attributed, to some extent, to the fact that the researcher is an insider in the field of enquiry and participants are aware she has experienced and witnessed both the positive and negative aspects of the role. The following section describes the emergence of the core category RELATIONSHIPS and how each of the categories are linked to this central variable.

## The emergence of the core category relationships

The goal of grounded theory is to facilitate the emergence of a theory from the participants' data that '... accounts for a pattern of behaviour which is relevant and problematic for those involved' (Glaser 1978, p. 93). It should also account for the variations in the participants' behaviour using the least amount of concepts ensuring parsimony and scope (Glaser 1978, p. 93). The core category is therefore the central variable identified in the data and is related to, has explanation for and is the link between all the other categories included in the theory (Glaser 1978, p. 93).

During the open and selective coding phases and as the process of constant comparative analysis progressed **RELATIONSHIPS** was identified as the core variable. **RELATIONSHIPS** is the glue that connects and integrates the other categories and explains the main issues and challenges that impact on transplant coordinators and their practice. **RELATIONSHIPS** meets the criteria for core category selection as described by Glaser (1978, pp. 94-96). These criteria are discussed below in terms of how the core category was identified in this study.

The core category must be central to the others, their properties and characteristics (Glaser 1978). Throughout the process of constant comparative analysis and following re-evaluation of the category **RELATIONSHIPS** it was obvious that this was central to the others as demonstrated earlier.

The category, its properties and characteristics also appeared frequently in the data, which is another criterion pronounced by Glaser (1978) for core category selection. This leads to patterns in behaviour being identified and ultimately the emergence of the category as the core variable. From the commencement of data collection and analysis the participants provided data suggesting that **RELATIONSHIPS** are fundamental to transplant coordinators and their practice. As the analysis progressed patterns in the data confirmed that **RELATIONSHIPS** were indeed essential for the categories KNOWLEDGE AND EXPERIENCE, THE ROLE and OUTCOMES to exist. All were dependent on the **RELATIONSHIPS** the transplant coordinators sought, developed and maintained.

Saturation of the core category also takes longer as the core category occurs more frequently in the data and is linked to all the other categories (Glaser 1978, p. 95). Saturation is said to have occurred when no new data or ideas can be added to the category. It is the point at which data collection becomes redundant (Polit & Hungler 1997). In grounded theory saturation occurs when theoretical sampling ceases to add any new information to the category, its properties and characteristics (Glaser 2002).

The core category **RELATIONSHIPS** was close to saturation following analysis of the first Delphi survey questionnaire, which was, confirmed when little new information could be added. However, in the early stages of the coding and analysis of the second survey a new subcategory, VIRTUAL RELATIONSHIPS, emerged. This was subsequently changed as further examination revealed it was actually a property of the core category. The second Delphi questionnaire confirmed that saturation had occurred and added richness and density to the data that had already been collected.

Meaningful links between each of the categories and the core variable is also a criterion used by Glaser (1978, p. 95) for core category identification. A number of links emerged to connect the category KNOWLEDGE AND EXPERIENCE with the core category **RELATIONSHIPS**. The attainment of KNOWLEDGE AND EXPERIENCE is often conditional on the **RELATIONSHIPS** coordinators have

with their colleagues and other health professionals. Participants also indicated that KNOWLEDGE AND EXPERIENCE is an anticipated consequence of the core category **RELATIONSHIPS**. With each personal interaction, coordinators are exposed to more opportunities to expand and develop their KNOWLEDGE AND EXPERIENCE. The reverse is also true, with many **RELATIONSHIPS** being developed and maintained because the coordinator has a level of knowledge and expertise, which is, sought out by colleagues and client groups including donor families, recipients, potential recipients and the general public.

KNOWLEDGE AND EXPERIENCE is also contingent on **RELATIONSHIPS**. Without peer support and education the 'hands on' aspects as well as the theoretical components required to facilitate THE ROLE in an efficient and safe manner would be compromised if the **RELATIONSHIPS** were inadequate. The attainment of KNOWLEDGE AND EXPERIENCE is usually a consequence of established **RELATIONSHIPS** although a number of participants also identified self-education as an important mechanism for gaining knowledge and expertise.

Similar links are evident with regard to the category THE ROLE. For transplant coordinators to actually practice effectively there needs to be supportive and functional **RELATIONSHIPS**. Many participants state that their practice demands considerable flexibility, consideration and support amongst all health professionals, allied health personnel and support staff.

Attributes of THE ROLE - advocacy, autonomy, challenges, credibility, intimacy of the job, leadership, power, respect, responsibility, trust and uniqueness are also strongly linked to the type and significance of the **RELATIONSHIPS** the coordinators engage in and cultivate. Supportive **RELATIONSHIPS** lead to increased job satisfaction and appreciation of THE ROLE attributes. Negative, unsupportive, aggressive or limited opportunities for **RELATIONSHIPS** lead to coordinators becoming frustrated, professionally isolated, overwhelmed with work demands, dissatisfied with the work climate and ultimately psychologically and/or physiologically stressed resulting in burnout and increased attrition rates.

OUTCOMES was also linked to the core category, as **RELATIONSHIPS** are the context in which positive OUTCOMES are usually achieved. Much importance was placed on teamwork and cooperation between the transplant coordinators and other health care providers. Many felt that positive OUTCOMES are achieved when all participants in the organ donation and transplantation fraternity are working to achieve a similar goal.

However, a number of donor coordinators expressed that they are in their roles to facilitate the wishes of the deceased and support the donor families. Alternatively the recipient coordinators see their role as one that advocates and supports recipients and potential recipients. Thus THE ROLE of transplant coordinators is to procure health organs for potential recipients although there are divided opinions as to which goals and hence which **RELATIONSHIPS** should take precedence.

There was also considerable reference to OUTCOMES for transplant coordinators with suggestions that inadequate working RELATIONSHIPS with colleagues and other health professionals led to poor, or in some cases, devastating OUTCOMES for transplant coordinators themselves. Examples of such included unsupportive managers, medical staff who were unhelpful or refused to acknowledge the coordinators' contributions, colleagues who were inconsiderate and inflexible and unappreciative clients. Many participants reflected on the devastating effects of work place bullying and bad behaviour whilst others referred to a lack of support, which left them feeling professionally isolated, frustrated, stressed, unappreciated and overwhelmed. Significantly, unwanted effects for some coordinators were feelings of depression, suicidal ideation, fatigue, burnout, marriage break-ups or the imminent need to resign.

RELATIONSHIPS was also seen to co-vary with the other categories demonstrating that the links between the categories and the core variable were interdependent and clearly apparent. Each category provided the framework and infrastructure on which the other categories were dependent. The most significant and influential category was the core category RELATIONSHIPS. It was readily apparent from the data that RELATIONSHIPS were the main source and avenue for the attainment of KNOWLEDGE AND EXPERIENCE. RELATIONSHIPS were also put forward as the most significant aspect of THE ROLE and the transplant coordinators' practice. Finally, the quality and development of RELATIONSHIPS was seen as the most important factor in determining the OUTCOMES.

Glaser (1978, pp. 95-96) suggests that the core category should be clearly discernible and have explanatory qualities, which are reflective of the substantive theory. He also states that the core category should have 'considerable carry-through' (Glaser 1978, p. 96). This was evident in the current study where the core category **RELATIONSHIPS** is unmistakably linked to the other categories and has explanation and fit in terms of the links between the categories and the

core category. The core category was also shown to have carry-through for the entire study. According to Glaser (1978) this means that the core category:

... does not lead to dead ends in the theory nor leave the analyst high and dry, rather it gets him [sic] through the analyses of the processes he [sic] is working on, by its relevance and explanatory power. He [sic] literally carries through his [sic] analysis based on the core's use (Glaser 1978, p. 96).

Glaser (1978, p. 96) also states that the core category should be completely variable and readily modifiable. Thus when those linked to the core category RELATIONSHIPS vary, the core category itself should also vary. An example of this was demonstrated earlier where it was shown that the transplant coordinators' level of KNOWLEDGE AND EXPERIENCE could influence the RELATIONSHIPS and types of interactions they have with their colleagues and other health professionals.

The final criteria put forward by Glaser (1978) to assist in the identification of the core category is that the category itself is part of the problem and is therefore able to explain some of its own variation. RELATIONSHIPS are a result of the interaction of many factors and are therefore part of the problem in defining and explaining the issues and challenges that impact on transplant coordinators and their practice. Factors affecting the other categories will also have an impact on the RELATIONSHIPS transplant coordinators engage in and the type and effectiveness of those RELATIONSHIPS. The symbiosis between the core category RELATIONSHIPS and the other categories is readily demonstrated in the study data. Participants indicated that they consider RELATIONSHIPS to be Interactive interdependent with the other categories.

Therefore **RELATIONSHIPS** are a vital component of all the other categories that emerged in the data. With each category dependent on RELATIONSHIPS for their existence and ongoing development, it is imperative that positive, supportive, meaningful and productive RELATIONSHIPS are established between coordinators, their client groups and other stakeholders.

Often these RELATIONSHIPS have to be established under difficult circumstances, particularly for donor coordinators. They are required to establish significant and meaningful connections with donor families, health professionals and the support personnel they interact with during the organ donation process. This requires considerable skill and confidence, as the coordinator needs to balance the needs of a grieving family with the demands of the organ retrieval process. Similarly, recipient coordinators are required to establish meaningful and ongoing **RELATIONSHIPS** with recipients, potential recipients and other relevant stakeholders. This is particularly important when facilitating the transplantation process. There are time constraints and significant logistical elements to negotiate with many individuals involved, including recipients and their families who are often anxious and in need of much support.

The properties of the core variable indicate it has strong links to all the other categories, with **RELATIONSHIPS** being identified as a condition of the other categories. **RELATIONSHIPS** therefore is the medium that links all the categories together. This is indicated by the fact that most participants believe that coordinators through their **RELATIONSHIPS**, both individually and as a team, can influence OUTCOMES in their practice, meet new and interesting people in their roles and gain valuable knowledge, expertise and experience from others working in the area.

There was also strong evidence to suggest that **RELATIONSHIPS** were the context within which the other categories become operational. Participants asserted that **RELATIONSHIPS** enabled them to increase their KNOWLEDGE AND EXPERIENCE, carry out, develop and expand their role and facilitate OUTCOMES. **RELATIONSHIPS** were also largely seen as positive and fulfilling aspects of the coordinators' practice, although there were many documented examples of unsatisfactory and even aggressive or toxic **RELATIONSHIPS** in the work environment. It was also suggested that **RELATIONSHIPS** enhanced the possibilities of positive OUTCOMES for both clients and transplant coordinators.

It was clear from the data that the core category also co-varied with the others through a symbiotic union of the four categories that had emerged from the study. There were numerous examples provided by the participants to suggest that the category **RELATIONSHIPS** was indeed the core category as it had fit, grab, scope, it worked, had relevance and modifiability as is required in a grounded theory study (Glaser 1978).

Constant comparative analysis together with the theoretical codes also identified that the core category **RELATIONSHIPS** was about affiliation, alliance, connection, interdependence and the interaction of effects. The properties of this category included the following types of **RELATIONSHIPS** evident in the data; supportive, unsupportive, aggressive and virtual **RELATIONSHIPS**. The characteristics of each are explained below.

Supportive RELATIONSHIPS - Characteristics of this type of RELATIONSHIP Supportive include: shared goals, good communication, respect, teamwork, trust, debriefing, peer support, compromise and flexibility, networking and job satisfaction.

Unsupportive RELATIONSHIPS - Characteristics emerging from the data Unsupportive suggested that professional isolation, non-supportive colleagues. communication, voice not heard, lack of acknowledgement, expendability, difficulties with colleagues and/or other health professionals and unhealthy competition were the main factors contributing to unsupportive work-related RELATIONSHIPS.

relationships

relationships

Aggressive RELATIONSHIPS - The characteristics of this type of toxic Aggressive RELATIONSHIP include: bad behaviour, offensive language, bullying, putdowns, being undervalued, expendability, non-supportive colleagues, minimal or no communication and psychological stress. There were also strong indications in the data to suggest that satisfactory RELATIONSHIPS were or could potentially be poisoned in aggressive, non-supportive and unfulfilling environments.

relationships

Virtual RELATIONSHIPS - Characteristics of this type of RELATIONSHIP were Virtual feelings of a deep spiritual connection or bond, intimacy, making a difference, the need to advocate on behalf of an unknown person, considerable intrinsic rewards Many organ donor coordinators expressed the and job satisfaction. characteristics of this type of RELATIONSHIP as one with strong emotional ties with deceased donors they have never known and for a few coordinators this also pertained to recipients they have never met. In the case of the deceased donor, there are vicarious connections with them through the donor family. For some recipient coordinators these virtual RELATIONSHIPS can be the connection they feel with unknown donors and donor families. This connection is often facilitated through shared information given to them by the organ donor coordinators about the deceased donor and their family. Similarly, organ donor coordinators may feel a connection with the recipients. This may be partly due to the romanticised images they have of the recipients and/or because of the information that is shared with them by the recipient coordinators.

These unusual RELATIONSHIPS that transplant coordinators appear to have with unknown individuals are similar to those that donor families and recipients have with each other. Even though these parties may never meet and may only have very limited information about each other there is an undeniable bond that exists between them. Like the donor families and recipients these virtual **RELATIONSHIPS** or **RELATIONSHIPS** 'via proxy' that the coordinators have are potentially very powerful and emotional connections, which can remain with coordinators for a lifetime.

At this stage of the analysis it became evident that the core category may also be a process. With this in mind the data was revisited to explore the possibility that the core category **RELATIONSHIPS** may in fact be a basic social process (BSP). Glaser (1978, p. 97) defines a BSP as having '... two or more clear emergent stages.' He also suggests that BSPs '... give the feeling of process, change and movement over time' (Glaser 1978, p. 97). It would appear that this may be the case in regard to the core category **RELATIONSHIPS**.

# **Emergence of the BSP - BUILDING RELATIONSHIPS**

Following further constant comparative analysis the core category **RELATIONSHIPS** was indeed found to be a basic social process (BSP). From the data it was clearly evident that there were changes in the social phenomena being studied that occurred over time (Glaser 1978). Glaser (1978, p. 97) uses a term called 'gerunding' to denote a BSP. He states that a 'gerund' gives the feeling of movement, process and change. Some examples of 'gerunds' are becoming, exploring, defaulting and cultivation each alluding to or representing changes occurring over time. Although Glaser (1978, p. 97) states that 'gerunds' are usually, but not exclusively, reserved for formal theories it was apparent that the core category **RELATIONSHIPS** did have a feeling of movement and process. Therefore discernable steps occurred over time and it was thought that adding a 'gerund' to the core category was both warranted and appropriate.

The 'gerund', which was added to the study's core category in order to denote a BSP, was building. *The Macquarie Concise Dictionary* (2004, pp. 152, 1014) states that to build is 'to construct something relatively complex by assembling and combining parts' and relationships as 'an emotional connection between people'. **BUILDING RELATIONSHIPS** by definition then consists of more than one stage and is in fact a complex process built over time with many layers or stages and component parts.

The BSP referred to as **BUILDING RELATIONSHIPS** because the process is a constantly changing phenomenon and a significant issue or challenge for transplant coordinators and their practice:

... as well as those very ... close relationships both with your colleagues and with other staff because it's a very powerful experience for everybody ... organ donation and the actual retrieval and I think you just don't get to relate to people in that way ... every day (DFG, p. 12, L. 22-

... the teamwork involved in caring for transplant recipients is just magnificent and to be a part of that team is very exciting (RFG, p. 14, L. 13-14).

There are a number of criteria identified by Glaser (1978) as being pertinent to core category and/or BSP selection as discussed in Chapter Three. They relate to the following three defining characteristics offered by Hutchinson (1986, p. 118) in stating that the core category or BSP must:

- Appear frequently in the data.
- Link the codes and categories together.
- Explain the majority of the variation in the research data.

**BUILDING RELATIONSHIPS** had two subcategories – THE HEALTH TEAM and THE CLIENT. Other examples of the BSP - BUILDING RELATIONSHIPS that emerged from the data included:

... one of the best things about the job ... was this incredibly close cohesive team and you knew no matter what time of the day or night it was you could phone your colleagues for back up which might sound like I'm contradicting myself a little bit when I said there was an expectation that if there were two donors in the hospital you'd do them both there may have been that expectation but at the same time there was never any problem with calling your colleagues for advice ... (DFG, p. 41, L. 18-26).

Even families that kids have died on the waiting list or have died post transplant you ring them up occasionally or you'll get a card in the mail ... the friendships that you gain ... are really quite incredible for me (RFG, p. 78, L. 9-12).

These examples exhibit the elements of process, movement and change, which are requirements of a BSP in a grounded theory study.

# Stage three - delimiting the theory

Glaser and Strauss (1967, p. 110) state that delimiting of the emergent theory occurs at the theory and category levels. At the theory level major modifications Theory & become less frequent as the researcher continues the process of constant comparative analysis where incidents and events are compared with each of the categories and their properties. This is achieved by removing non-relevant properties whilst integrating and elaborating on the properties pertinent to the emergent theory. This action also ensures that the somewhat cumbersome and

category levels

detailed outline of the interrelated categories, which make up the theory, is condensed to a succinct and relevant substantive theory through the process of reduction (Glaser & Strauss 1967). Modifications occurring in the later stages of analysis are essentially addressing and clarifying the logic of the developing theory (Glaser & Strauss 1967, p. 110).

At the category level the theory is delimited or reduced when the category is found to be theoretically complete or saturated (Glaser & Strauss 1967, p. 111). Theoretical As incidents emerging from the research data are constantly compared with each other, the categories and their properties, only data that is relevant to the category and/or its properties is included. Here delimiting of the theory at the category level was an ongoing process. Following the initial open coding of the focus group interviews, subsequent data was only included if it added richness, clarity or density to the category and/or its properties.

completeness

Category saturation varied with a number of categories appearing to be saturated Saturation following the analysis of the focus group interviews. Others including the BSP -BUILDING RELATIONSHIPS took much longer. Some became saturated following analysis of the first Delphi survey questionnaire and others were saturated by the completion of the second survey analysis. As the researcher was immersed in the data it was a relatively easy decision regarding whether or not incidents, events or new information should be included in the category or its properties.

The other characteristic of grounded theory that assisted in reduction at the Category category level was that the codes, preliminary categories and categories were subsumed into higher-level concepts. Therefore the number of actual categories requiring the comparison of incidents or events as well as saturation obviously decreased as the theory evolved. This enabled data collection to be focused only on the remaining categories. The process of focused data collection is referred to in grounded theory methodology as theoretical sampling. However, one must be aware that there is potential for new data to emerge, which may not fit into existing categories and must therefore be prepared to create a new category should this circumstance arise.

Theoretical sampling too is a method of delimiting the theory, as only individuals. Theoretical situations or literature that will add to the BSP, the categories, their links and properties are sought out. Therefore only relevant data that will add density and advance the emerging theory is collected. In this study theoretical sampling was

sampling

facilitated by two methods. The first of these was accessing the available literature on transplant coordinators and their practice to ascertain if there was data in the literature that would advance the categories and their properties. The second method was using two rounds of the Delphi survey questionnaires. The first survey was informed by the data analysis of both the focus group interviews and the available literature. The second survey was also informed by the analysis of the first round of the Delphi survey questionnaire.

As the constant comparative method of analysis progressed and theoretical saturation of each of the categories and the BSP were methodically achieved, the properties of each of the categories together with their links were identified. This fundamental process of grounded theory also enabled assessment of which of the categories, if any, were not required in the emergent theory thus potentially reducing the number of categories.

Reduction was also achieved through the process of constant comparative analysis whereby similar codes that emerged from the data were grouped together to form preliminary categories, which were combined to form categories. This procedure continued until the researcher was able to 'formulate the theory with a smaller set of higher level concepts' (Glaser & Strauss 1967, p. 110). The Higher-level concepts subsequent reduction in the categories also resulted in the delimiting of the terminology and the text used to describe the theory.

The reduction in the theory, its terminology and text also meant that the substantive theory could potentially be used in other areas of enquiry or situations and possibly contribute to a formal theory. Glaser and Strauss (1967, p. 111) declare that there are '... two major requirements of theory: (1) parsimony Parsimony & of variables and formulations, and (2) scope in the applicability of the theory to a wide range of situations ... Whilst the context in which transplant coordinators operate is unique the process of BUILDING RELATIONSHIPS is universal and therefore transferable to other areas of employment and thus could contribute to a formal theory. The only possible exceptions are the virtual relationships that coordinators experience.

For example, being an astronaut can be perceived as a unique profession. However, the principles of the theory presented could still be applied - each of the astronauts bring a level of KNOWLEDGE AND EXPERIENCE in terms of their role and the RELATIONSHIPS they seek to build within their occupational environment. Their role is also the context in which their working **RELATIONSHIPS** are developed and maintained. Finally, positive and efficient OUTCOMES rely on the astronauts' abilities to facilitate functional and effective RELATIONSHIPS with their colleagues, employers and those that educate and support them.

In relation to this study the first of these requirements was achieved in the first three stages of the analysis cycle. There were initially five categories following the open coding of the recipient coordinator focus group interview data, which increased to six following similar coding of the donor coordinator focus group interview data. Selective coding of the Delphi survey questionnaires saw the number of categories that had emerged in the study settle at four.

This process facilitated the emergence of a theory that is rich, dense and has explanation in terms of the main issue and/or challenge that impacts on transplant coordinators and their practice. It also allows for the possibility of the theory being useful in other areas of practice within the health sector. For example the theory may have scope, fit and applicability for the triage nurse in an emergency department, as they are responsible for coordinating patient care. The retrieval nurse coordinating proceedings at a disaster may also benefit from this theory on BUILDING RELATIONSHIPS. The theory could potentially apply to a number of scenarios and/or professions adding knowledge and understanding to these areas of practice.

# Stage four – writing the theory

The final stage of the constant comparative cycle - stage four - is writing the Writing the theory (Glaser & Strauss 1967, p. 105). The movement from delimiting the theory to this stage is not clearly delineated but can be complex and evolves over time. As the researcher moved into this stage, four categories had emerged from the data and appeared to have explanation, scope and fit in relation to the issues and challenges that impact on transplant coordinators and their practice:

- 1. KNOWLEDGE AND EXPERIENCE
- 2. THE ROLE
- 3. OUTCOMES
- 4. BUILDING RELATIONSHIPS

The main issues and/or challenges that impact on transplant coordinators and their practice are BUILDING RELATIONSHIPS. As the identified BSP, this

involves the interaction of effects between the categories KNOWLEDGE AND EXPERIENCE, THE ROLE and OUTCOMES. This very interaction is the essence of the theory. KNOWLEDGE AND EXPERIENCE provides the information and expertise the coordinators bring to their **RELATIONSHIPS**, THE ROLE is the environment in which their interactions take place and OUTCOMES are the results of these exchanges and can be positive and/or negative. The following discussion expands on the theory.

The **RELATIONSHIPS** that coordinators build within THE ROLE are also influenced by THE ROLE attributes. Advocacy, autonomy, challenges, intimacy of the job, leadership, power, respect, responsibility, trust and uniqueness — may also be contributing factors which attract certain personality types to the position. For example, individuals seeking employment opportunities where judicious thinking, autonomous practice and high levels of responsibility are required, may be drawn to this type of role.

RELATIONSHIPS that coordinators build, together with their perceptions of THE ROLE attributes are significant indicators of the level of job satisfaction they derive. The qualities of the coordinators' RELATIONSHIPS are also influenced by a number of factors, which are both within and beyond their control.

Factors within their control include their willingness to listen, to contribute in a meaningful way, to cooperate, to be understanding and to communicate their needs and wishes clearly and concisely. All these add to the integrity and effectiveness of **RELATIONSHIP** building. Factors beyond the coordinators' control include work conditions, environmental factors, difficult or unforseen circumstances and the negative or inappropriate behaviour of others. These have the potential to be significant impediments to the building of **RELATIONSHIPS**. The categories KNOWLEDGE & EXPERIENCE, THE ROLE and OUTCOMES all depend on the quality of the **RELATIONSHIPS** that transplant coordinators seek to build, develop and maintain.

Principle **RELATIONSHIPS** formed within the transplant coordinators' practice are those with colleagues, other health professionals, client groups and the unique virtual **RELATIONSHIPS** that a number of the coordinators reported experiencing. Four properties that emerged as part of the **BSP – BUILDING RELATIONSHIPS** were: supportive, unsupportive, aggressive or toxic and virtual **RELATIONSHIPS**, each of which was discussed earlier. Examined below are the links between the BSP and the other categories in the theory.

## Knowledge and experience

The transplant coordinators' education, knowledge, experience, qualifications and skills preparation, all of which develop in stages, are seen as contributing factors to the mechanisms and incentives for **BUILDING RELATIONSHIPS** and functioning effectively in their role. There is also considerable concern with regard to transplant coordinators who are employed without nursing or medical qualifications. A number of study participants, particularly those from the recipient coordinator cohort, state that this leads to significant difficulties in regard to service delivery, building professional alliances and OUTCOMES.

This view, however, was not the only one represented in the data. A number of respondents strongly argued that those from other professional backgrounds contribute alternative skills and attributes to THE ROLE, which are equally significant. It should also be noted that the process of organ donation and transplantation is not the only aspect of the transplant coordinators' role. Australasian transplant coordination history and current practice show that there have been significant and substantial contributions made to this field by coordinators with neither nursing and/or medical backgrounds.

It is also evident that the category KNOWLEDGE AND EXPERIENCE is a condition of **BUILDING RELATIONSHIPS**. Without a certain level of knowledge and expertise, transplant coordinators are seen to lack credibility and professional status, particularly amongst their colleagues and the medical profession. Conversely, KNOWLEDGE AND EXPERIENCE is also seen to be contingent on the **RELATIONSHIPS** that transplant coordinators foster with their colleagues and other health professionals. The main reason for this is that a large proportion of the transplant coordinators' education, KNOWLEDGE AND EXPERIENCE is obtained 'on the job'. Coordinators therefore rely on colleagues and medical staff for basic and ongoing education and training. Supportive and functional **RELATIONSHIPS** are, for this reason, highly important to these health care professionals.

KNOWLEDGE AND EXPERIENCE is also a consequence of the **RELATIONSHIPS** that transplant coordinators build. With each encounter there is an opportunity to expand their knowledge, expertise, skills and experiences. In positive circumstances this expansion of knowledge and professional competence not only improves the service that transplant coordinators deliver but also fosters strong productive links with colleagues, other health professionals

and client groups. This contributes to professional development and passion for THE ROLE. In less favourable circumstances opportunities for professional advancement in terms of the acquisition of KNOWLEDGE AND EXPERIENCE are hampered when **RELATIONSHIPS** are non-existent, unsupportive or aggressive in nature.

The category KNOWLEDGE AND EXPERIENCE and the **BSP – BUILDING RELATIONSHIPS** also co-vary, thus ensuring a symbiotic alliance between these two variables. In other words KNOWLEDGE AND EXPERIENCE expands and develops when positive **RELATIONSHIPS** are built and nurtured. However, **RELATIONSHIPS** are also improved with increased KNOWLEDGE AND EXPERIENCE. Thus KNOWLEDGE AND EXPERIENCE and **BUILDING RELATIONSHIPS** have a beneficial effect on each other. Examples of the properties and/or characteristics of the category KNOWLEDGE AND EXPERIENCE, which enhance the links with the **BSP – BUILDING RELATIONSHIPS**, include - coordinators taking responsibility for their ongoing professional development, advancement and improvement and coordinators who network, develop strong alliances and engage in team-related activities to advance their level of expertise.

#### The role

THE ROLE of transplant coordinators is a contributing factor in **BUILDING RELATIONSHIPS**. As with all interactions, there needs to be an environment in which **RELATIONSHIPS** can develop and evolve. Three properties emerged in this category:

- 1. **The work environments** which included the political-economic, socio-cultural, medico-legal, physical and psychological environments.
- Work demands and conditions including excessive workloads, on call demands, professional isolation and occupational health and safety issues.
- THE ROLE attributes encompassed the coordinators' level of job satisfaction together with the intrinsic and extrinsic factors affecting their participation in THE ROLE.

THE ROLE is seen as a condition and a source of **RELATIONSHIPS**. Without this type of environment, **RELATIONSHIPS** with donor families, recipients, potential recipients and other health care providers working in the field of organ

donation and transplantation would not exist. THE ROLE is also contingent on **BUILDING RELATIONSHIPS** as it is only through the teamwork and cooperation of many individuals working together that the transplant coordinators are able to facilitate the organ donation and transplantation process and carry out other aspects of their professional role.

#### **Outcomes**

Data analysis suggests that the goals of the transplant coordinators are to provide positive OUTCOMES for their client groups whilst also improving their own work conditions and professional and/or personal OUTCOMES. These goals are largely reliant on the transplant coordinators' abilities to build positive and sustainable **RELATIONSHIPS** in the work environment.

OUTCOMES are seen as a condition and source of **RELATIONSHIPS**. Participants indicate that a substantial number of **RELATIONSHIPS** they engage in are only possible due to the generosity of donors and their families who provide the organs for transplantation, and because there are potential recipients in need of transplants. Without the stated client groups these types of **RELATIONSHIPS** would not be possible.

OUTCOMES are also a consequence of **RELATIONSHIPS** as it was felt that constructive **RELATIONSHIPS** enabled effective teamwork, which is a major contributor to successful OUTCOMES. OUTCOMES relate to client issues in terms of organs donated and subsequent transplants, as well as transplant coordinator OUTCOMES. **BUILDING RELATIONSHIPS** is significant in terms of ongoing support and networking for transplant coordinators and is necessary to ensure positive OUTCOMES for these health care providers and their clients.

Furthermore, OUTCOMES are shown to co-vary with **BUILDING RELATIONSHIPS**. OUTCOMES provide feedback to the transplant coordinators, which in turn enables them to re-evaluate and modify their practice and/or **RELATIONSHIPS**.

# Implications of the findings

The theory that emerged from this study indicates that the **RELATIONSHIPS** transplant coordinators build are fundamental to their practice. Therefore, to enhance the potential for transplant coordinators to build and/or maintain positive and effective **RELATIONSHIPS** the following areas must be addressed.

# The balance between professional and private life

Significant challenges face coordinators in keeping a healthy balance between employment commitments and their private lives due to such factors as the unpredictable nature of the work, on call commitments, the after hours component of THE ROLE, the long and extended hours involved and sleep deprivation. Furthermore, the considerable demands of THE ROLE have implications for the coordinators' professional and personal **RELATIONSHIPS**. This would suggest that consideration needs to be given to one's ability to change focus outside of work hours and maintain an appropriate balance in terms of personally rewarding experiences and employment commitments.

This can be supported by management through implementing fair and equitable on call commitments and after hours work, ensuring availability of enough staff, allowing staff to have time off for personal events where possible, for example school open days, going to the doctor with a spouse or weekend sporting commitments. In other words, the development of a more family and/or individually supportive work environment that aims to accommodate coordinators' family/personal life and interests is necessary to address this imbalance.

#### **Professional isolation**

Coordinators repeatedly state that it is the connection they have with their client groups and colleagues that give them a sense of well-being and job satisfaction. Thus, perceived or actual professional isolation has serious consequences for those involved in this occupation. It is an issue that should relatively easily be addressed particularly in these times of enhanced technological communication techniques and the current drive towards networking. Furthermore, addressing this challenge may involve working out ways to build supportive and interactive **RELATIONSHIPS** as well as providing more financial assistance to attend conferences, especially for those who are in extremely isolated positions, such as sole practitioners. Support networks, which allow these individuals to feel comfortable with 'checking in' and asking for assistance if necessary, would be beneficial, as would specific knowledge regarding support networks within their geographical location.

# Acknowledgement and respect

Acknowledgement and respect from peers, managers and other health professionals is important to transplant coordinators. Some believe there is a lack of acknowledgement and appreciation for coordinators themselves as well

as the complex work they perform. Blumenthal (2007) highlights this when discussing the counselling skills of donor coordinators:

Another important implication for management is the organization's recognition of the donation coordinators as being effective counselors. Donation coordinators seem to possess the critical skills needed in order to establish a therapeutic alliance with donor families — whether they learned these skills from their backgrounds in nursing, prior life experiences, or on the job ... their counseling skills are equivalent to those of persons who have had extensive clinical training and course work in counseling (Blumenthal 2007, p. 20).

Coordinators contribute a high level of expertise, which enables them to connect with their clients and therefore build therapeutic **RELATIONSHIPS.** Greater acknowledgement of this from surrounding health professionals would assist in them feeling more appreciated and valued by both management and their peers.

This can be facilitated through measure such as developing a culture of respect, with management and colleagues taking every opportunity to acknowledge coordinators, making time to listen more often and by taking an appropriate interest in each of the coordinators on staff. Furthermore, this could also be addressed by asking coordinators for their input, ideas and opinions. Other ways to broaden the coordinators' expertise and demonstrate they are valued, is to give them opportunities to participate in some of the more exciting aspects of THE ROLE, for example being on a committee involved in an activity the coordinator is passionate about.

#### Workplace bullying and its effects on relationships

The undesirable component of workplace bullying within the transplant coordinators' practice leads to aggressive and toxic **RELATIONSHIPS**, which are shown to be prevalent in many interactions between coordinators and medical practitioners. Such **RELATIONSHIPS** are also reported to exist amongst transplant coordinators themselves and ultimately result in poorly functioning work environments, losses in productivity, absenteeism, psychological stress, resentment and burnout.

The presence and effects of workplace bullying within organisational settings is becoming a well-recognised issue, as is the importance of appropriately addressing it (Hutchinson, Vickers, Jackson & Wilkes 2006; Department for Victorian Communities 2005). Harassment of any kind is unacceptable in all workplaces, which are now encouraged to take a pro-active rather than reactive approach to this problem (Department for Victorian Communities 2005).

Prevention and early intervention are essential if these behaviours are to be effectively eradicated (MacIntosh 2006). Occupational health and safety legislation is one mechanism currently used to address bullying and victimisation in the workplace (Mitchell 2006; Interagency Round Table on Workplace Bullying 2005).

## Fostering relationships

As **RELATIONSHIPS** with client groups are fundamental to transplant coordinators and their practice it is necessary that management foster these **RELATIONSHIPS** by ensuring that coordinators have adequate time with these individuals. Fostering supportive **RELATIONSHIPS** between transplant coordinators themselves is also fundamental to a professionally rewarding and satisfactory work environment. This may be achieved through team building, networking and social interaction.

## Factors contributing to a positive work environment

Also seen to enhance the development and maintenance of effective workplace **RELATIONSHIPS** is a range of issues pertaining to a positive work environment. These include supportive colleagues, formal or informal opportunities to debrief, empathetic managers, support and acknowledgement from other health professionals, a connection with client groups and the ability of coordinators to derive meaning and satisfaction from their work and resulting **RELATIONSHIPS**. This type of environment would be the result of positive and purposeful workplace negotiations.

It is appropriate to make formal debriefing with independent practitioners a regular component of THE ROLE, thus normalising the process as one that addresses the occupational health and safety issue of 'compassion fatigue' and burnout. This would also give coordinators an opportunity to discuss the challenges of their work environment and the often unusual and tragic circumstances they deal with. The demands of dealing with grieving families, potential recipients who are desperate for a life-saving organ, who may die on the list or alternatively have less than ideal OUTCOMES following surgery, together with the practical and political aspects of THE ROLE cannot be underestimated. This coupled with prompt and appropriate action to address difficulties where possible may improve OUTCOMES not only for clients but also coordinators themselves.

Formal debriefing is only one means of providing support to transplant coordinators. There needs to be more attention given to the development of supportive teams and work practices in order to advance service delivery and support those at the 'coal face'. As discussed previously, this is a demanding area of employment with the potential for significant physical and emotional costs if coordinators are not supported in their role.

Furthermore, the emotional 'fragility' of people when they are exhausted must be appropriately recognised in the work situation. Holtkamp (2002) suggests that:

The emotional cost of caring for donors and donor families must be recognized by those with positional power to address such issues. Caring for the caregiver is as much about reverence for life as is caring for the recipient, the donor, and the donor's family (Holtkamp 2002, p. 189).

This challenging health care environment that demands a distinctly 'abnormal' level of both physical and mental capacity of employees must be made as 'accommodating' as possible. Excessive workloads and on call commitments need to be reduced to levels that are not only equitable, but also comply with occupational health and safety guidelines. Organisational support in the form of safe working conditions and practices, line management acknowledgement and encouragement, appropriate remuneration and staffing levels together with adequate 'back up' cover are not only desired but are essential if a healthy and enthusiastic work force is to be maintained.

There should also be opportunities for the inclusion of coordinators in peer support situations. To achieve this, the workplace ethos must positively foster and demand a high level of respect amongst all employees. Managers must also be pro-active in addressing issues of harassment through such means as appropriate publicity and customised programs.

# **Dissemination of findings**

For a study to inform, be debated and/or influence practice at all levels and generate change, research findings need to be disseminated to those that have the power and expertise to use the information in a constructive manner. This includes measures such as influencing policy, implementing appropriate procedures and the development of curricula that ensure current knowledge, and research findings are available to meet the continuing education and practice needs of those in the field. Opportunities exist to present these research findings to colleagues and other interested parties at conferences, workshops and

courses locally, nationally and internationally. Table 8.2 shows the plan for the dissemination of findings.

LOCAL	NATIONAL	INTERNATIONAL
SAODA	National Organ Donation Collaborative	ITCS Conference
Local recipient coordinators	National Clinical Task Force	NATCO Conference
SATODAC	Australians Donate	ETCO Conference
TNA education sessions – SA Branch	International Course for Organ Donor & Recipient Transplant Coordinators	TSANZ Conference
	ATCA/TNA Annual Conference	ISHLT Conference
	ACCCN Annual ICE Meeting	New Zealand organ donor coordinators
	National organ donation agencies	New Zealand recipient coordinators
Education sessions to staff in local ICUs and theatre suites	Publish in the peer reviewed journal: Transplant Nurses Journal	Publish in the peer reviewed journal: <i>Progress</i> in <i>Transplantation</i>
	Publish in the peer reviewed journal: <i>Australian</i> <i>Critical Care</i>	Publish in the peer reviewed journal: American Journal of Transplantation
	National recipient coordinators	

Table 8.2: Dissemination of research findings

# Local dissemination of findings

The findings of this research will be presented to organ donor coordinators at SAODA and the local recipient coordinators. They will also be presented at one of the education sessions conducted by the South Australian branch of the

Transplant Nurses' Association Inc. Medical and nursing staff from the ICUs and theatre suites at the local metropolitan hospitals, where organ retrievals take place, may also be interested in the findings, as may members of the South Australian Transplantation and Organ Donation Advisory Council (SATODAC).

### **National dissemination of findings**

The findings of this research should also be presented to the National Organ Donation Collaborative and the National Clinical Task Force, which has recently been commissioned to look at organ and tissue donation in Australia. Issues and challenges affecting transplant coordinators potentially have an effect on aspects of the organ donation and transplantation program.

Other possible organisations, which may be interested in the findings, include Australians Donate – Australia's National Organ and Tissue Donation and Transplantation Network, and the Australian College of Critical Care Nurses (ACCCN). A presentation will also be made at the combined Australasian Transplant Coordinators' Association and Transplant Nurses' Association Annual National Conference to be held in Melbourne, Australia 2007.

The International Course for Organ Donor and Transplant Recipient Coordinators held bi-annually in Adelaide, Australia and the Australian College of Critical Care Nurses Institute of Continuing Education (ICE) Meeting held annually in Australia are further dissemination sources. The *Transplant Nurses Journal* and *Australian Critical Care Journal*, which are peer reviewed Australian publications, may also be appropriate avenues for the distribution findings. Finally, staff from organ donation agencies, link nurse programs and recipient coordinators in hospitals throughout Australia may also wish to be informed of the study outcomes.

### International dissemination of findings

Submissions of papers to international peer review journals will also be made. Journal submissions to consider include: *Progress in Transplantation* and the *American Journal of Transplantation*.

As the research is the first of its kind in Australia and New Zealand there will be opportunities to present findings internationally. Such may include: the International Transplant Coordinators' Society (ITCS) conference, North American Transplant Coordinators' Organisation (NATCO) conference, European Transplant Coordinators' Organisation (ETCO) conference, Transplant Society of Australia and New Zealand (TSANZ) conference or the International Society of

Heart & Lung Transplantation (ISHLT) conference. The findings will also be presented to the New Zealand organ donor and recipient coordinators.

## Limitations

The importance of disclosing the limitations of a study cannot be underestimated. It enables other researchers participating in a similar journey to address or at least prepare for the actual and potential issues they may encounter.

## Organ donor coordinators and recipient coordinators

The need to have both organ donor coordinators and recipient coordinators in the one study cohort is a limitation that is known to the researcher. There are two reasons for this. Firstly, there are limited numbers of each of these types of coordinators in Australia and New Zealand and to ensure there were adequate participants in the study, the two types of coordinators were combined for this research, which increased participant numbers. Furthermore, as the coordinators are few in number they are also very well known to each other. To have a study cohort that represents either the organ donor coordinator population or the recipient coordinator population, is difficult from a confidentiality perspective as it may be relatively easy for the participants to identify each other in the data.

# Self selection of transplant coordinators into the study

A further limitation is the self-selection of participants into the study. As the roles of transplant coordinators are so diverse, and in many cases poorly defined, the researcher set out the basic inclusion and exclusion criteria for the study. If the transplant coordinators believed they met the inclusion criteria and were willing to participate then they were included. This lead to the use of interested participants only and the associated risk that their perspectives may cause the data to be skewed. It is felt that this risk is minimised due to the number of participants who gave their consent to participate in the research.

#### Australian and New Zealand transplant coordinators

The use of coordinators from both Australia and New Zealand may also be a limitation of the study. Significant differences between the countries may have impacted on responses of participants in both the focus group interviews and Delphi survey questionnaires. There are certainly political, geographical and functional differences regarding some aspects of organ donation and transplantation between the two countries. However, it could be cogently argued

that these differences are no more problematic than the differences between the states and territories of Australia.

The New Zealand coordinators are included for three reasons. There is an arrangement whereby organs are shared between the two countries therefore both countries are included on each other's rotation lists for organ allocation. Essentially, both jurisdictions operate as a functional unit in respect to the field of organ donation and transplantation. The New Zealand transplant coordinators are also an integral part of the two professional bodies ATCA and TNA and therefore are seen as professional colleagues in transplant coordination circles. The final and most important reason for their inclusion in the study is that the researcher believes they had a significant contribution to offer.

### Imbalances in the study cohort

The low numbers of male and non-nurse participants are also a limitation. It is difficult to make any definitive inferences and/or recommendations regarding these two groups of participants, as they are under-represented in the study cohort. The results with respect to the males and non-nurses, as stated throughout the study, need to be reflected on cautiously.

#### Further research

The findings from this research and the literature review conducted as part of the study have provided information for further research involving transplant coordinators and their practice. These include:

Replicating this study with transplant coordinators from other parts of the globe and comparing the findings with those of the Australian and New Zealand participants in this study.

The research could be modified by separating the transplant coordinator roles into a study that looks at the organ donor coordinators' issues and another that addresses recipient coordinator issues. To obtain adequate participant numbers in these groups the researcher would need to include transplant coordinators from other nations in their cohort.

There was a lack of research in the literature concerning transplant coordinators, particularly recipient coordinators. Thus there is considerable scope for research into most aspects of the transplant coordinators' roles and experiences.

As there was considerable debate in the current research relating to whether transplant coordinators should be registered nurses, it would be interesting to research the non-nurses practicing as transplant coordinators and compare the findings with coordinators who have nursing qualifications. As the current study only had five non-nurse participants a study with a larger non-nurse cohort may be more informative. To obtain an adequate number of non-nurses practicing as transplant coordinators, participant recruitment would need to be a global undertaking.

Research on transplant coordinators could also be conducted using different theoretical perspectives, for example critical social theory, phenomenology, ethnography or empirical research using statistical analysis.

Since there was a significant gender imbalance in this research with only eleven males in the sample, it may also be interesting to conduct a study which compares the male perspective with that of the females concerning issues and challenges that impact on transplant coordinators. Again, to obtain a larger number of males in a study cohort, participant recruitment would be a global undertaking.

## Conclusion

In this chapter the properties of each of the categories together with the links between the categories and the BSP were identified using the Six Cs, Interactive Process and Cutting Point theoretical coding families. This also facilitated the emergence of the broad aspects of the theory and the BSP – BUILDING RELATIONSHIPS. This was followed by a discussion on delimiting the theory, which occurred during each stage of the constant comparative analysis cycle in the study and ultimately resulted in a theory that had parsimony and scope. The fourth and final stage of the constant comparative analysis cycle – the writing of the theory – was then presented.

The emergent theory of the challenges that transplant coordinators face relates to the building of **RELATIONSHIPS**. This theory also discovers how KNOWLEDGE AND EXPERIENCE, THE ROLE and OUTCOMES impact on the building of these **RELATIONSHIPS** in an interdependent manner.

This theory has explanation, scope and fit with respect to these health care professionals and their practice. In essence, the study emphasises that the

transplant coordinators' role is complex, demanding and unusual in terms of the context in which they practice.

The experience of being a part of this unique group – of being a 'puzzle person' – has provided the great privilege of this opportunity to comprehensively examine its diverse characteristics. Adding to the acknowledged small bank of existing literature is but one beneficial achievement of this study. The provision of a voice for this professional group is another. The biggest achievement, however, lies in the opportunity presented for both refinement and reformation to aspects of the transplant coordinator's role. The undertaking of this would be yet another remarkable accomplishment in the fascinating history of transplant coordination.