

# Chapter 1

## Transplant coordinators

### Introduction

In this new millennium we are faced with ongoing and new challenges particularly in the context of science, medicine and technology. The recent past has brought extraordinary advances in these areas, which have made significant differences to many individuals and communities. These advances include the possibilities of cloning both embryonic and adult stages of human life, in vitro fertilisation, genetic manipulation (Somerville 2000, p. 3), organ donation and transplantation, advanced technology to ventilate critically ill patients, undertake stem cell transplants, and finally the ability to detect and treat cancer and other life-threatening illness earlier and more effectively.

It is in this technological and scientific context that organ donation and transplantation has become more commonplace and an accepted form of treatment for end stage organ failure. Since the early 1970s modern medicine, pharmacology, legislation and social acceptance have resulted in transplantation becoming a reality for people who otherwise would have died or at the very least lead poor quality lives. Crucial to this process and to the advancement of organ donation and transplantation has been the contribution made by health care professionals known as transplant coordinators (Elick 1997).

Although transplant coordinators have been described as the linchpin of transplant services (Elick 1997) there is limited research on the roles and functions of these health care professionals. This view is also supported in part by Holtkamp (2002), who states that with the exception of a few romanticised television documentaries depicting coordinators and/or doctors delivering life saving organs for transplantation under the cover of darkness, there is limited recognition given to organ recovery and those involved in the process. Yet all are essential to the success of transplant programs worldwide.

Through their commitment, teamwork, organisational and networking skills, coordinators have assisted in the facilitation and expansion of organ donation and transplantation. Although there has been extensive medical research

undertaken in the field there remains a paucity of literature on any aspect of the role of transplant coordinators.

Transplant coordinators are the health care professionals who facilitate the process of organ donation and transplantation. They witness the best of the human spirit, as a grief stricken family consent to organ donation in order to save or improve the lives of others. They also observe the exhilarating joy of a recipient when they are given a life-saving organ. The father of liver transplantation and well-respected surgeon Thomas E. Starzl, said, 'As I grew older, transplantation became a very large miracle, perhaps the least anticipated and potentially the most important one in the history of medicine' (Starzl 1992, p. 3).

Coordination or organising a process or activities is not a new or unusual phenomenon. There are countless examples of roles that encompass such activities, for example the triage nurses in the emergency department, the program director of an Olympic games, the head of the fire service at a major disaster and the director of a finance department. These all have a role to play in leadership, coordination and organisation. However, the role of the transplant coordinator is different.

It is the context within which these health care providers operate that makes them and their role unique. Donor and recipient coordinators facilitate a process that gives life from death. They are the individuals who coordinate a miracle of modern medicine that enables several people to live or improve the quality of their lives.

At any time of the night or day the transplant coordinators may be called to facilitate the organ donation and transplantation process, a process that will be life changing, not only for donor families and recipients but also for anyone intimately involved. As is clearly made evident by Starzl (1992, p. 4) one cannot participate in this field and not be touched or changed by it. His intriguing 'puzzle people' concept refers to those who have had transplants, as well as the effects on surgeons and physicians who are involved in the process - a process that the transplant coordinators are also intimately involved in:

During those years, the patients were not the only puzzle people who were being forged. The surgeons and physicians also changed – not so rapidly, because their own lives were not at stake, but inexorably, because the lives of others were in their hands. Some were corroded or destroyed by the experience, some were sublimated, and none remained the same (Starzl 1992, p. 4).

When speaking with transplant coordinators, one realises that their experiences in the role have also left a permanent imprint on their psyche that may never be erased. You are no longer the same once you have been a part of what is sometimes the most exhilarating and uplifting experience of your professional life or conversely one of the most devastating. One cannot work with donor families and recipients and remain unaffected by the experience; it is inconceivable.

A poignant story by Starzl (1992) from his book *The Puzzle People* demonstrates the connection he felt and continues to feel with one of his patients. She was a nineteen-month-old girl named Julie Rodriguez on whom he did a liver transplant to replace her cancerous liver. This operation was performed prior to when it was recognised that small deposits of tumour could metastasise in other areas of the body. This little girl is described as a 'metaphor for courage and human progress' (Starzl 1992, p. 166). He watched helplessly as Julie struggled against the recurrent cancer that had invaded her small and vulnerable body. Further surgery and chemotherapy were unable to combat the disease that was to kill her 400 days post-transplantation. A famous Swedish artist painted a symbolic memorial of Julie - a picture of 'a child bathed in sunlight, picking long-stemmed flowers' (Starzl 1992, p. 167). The picture was hung in the hospital ward for a number of years and over time became damaged. Starzl (1992) had the painting restored and took it home:

It has a position of honor in my bedroom, placed by a window where it catches the first rays at dawn. When I die, I will leave it to the person who is closest to me. Still pock-marked by the earlier damage, it is the dearest possession I have (Starzl 1992, p. 167).

This story is a powerful reminder of the impact that organ donation and transplantation can have on the health professionals working in the area.

Most transplant coordinators, if not all, have similar stories to tell. Some of these tales will describe the great sadness or the overwhelming jubilation they have witnessed or they themselves have experienced. Others will recall the teamwork; the funny moments, difficulties encountered or the incredible and often overwhelming tiredness coordinators feel, when organising the organ donation and transplantation process. Most will talk about the connection they felt with the donor family and/or the recipient(s). All are mindful of, and have to deal with, the great paradox of organ donation and transplantation, that a life has to end for others to live. One person's disaster is another person's miracle and it is the coordinators who are involved at all stages of that continuum of life and death.

Each coordinator will deal with their emotions in their own unique way as is shown in the following extract from an article titled 'The Donor Coordinator – the “caring face” of transplantation’ which describes how a donor coordinator honours the donors she deals with:

When she returns home, Marnie lights a candle – a small but significant gesture she performs after every organ donation. This small fact – of the lighting of a candle – is a touching tribute from the donor coordinator to the precious life that has ended, and yet extended to others (ORGANisation 2001, p. 8).

## **Contextualising the study**

In the early 1970s when successful organ transplants started being performed worldwide, it became apparent to transplant unit staff that there was a need for a coordinator to oversee the organ donation and transplantation process (Elick 1997). This person was referred to as the transplant coordinator by the kidney retrieval teams (Elick 1997). Elick (1997, pp. 325-326) broadly defines transplant coordinators as ‘persons who facilitate the transplant process – from donor identification and organ procurement to implantation and follow-up recipient care.’

The role of the transplant coordinator was first established in the United States of America in the early 1960s (Wight 1991). The world’s first full-time organ procurement coordinator was Paul Taylor (an American of negro origin) who was initially employed in 1962 to assist with metabolic studies in the research laboratories (Starzl 1992, p. 337). He soon became an indispensable team member involved with all the research studies in the laboratories. Like the other professionals involved, Taylor too was passionate about transplantation and ultimately became an organ procurement coordinator. His role was to visit hospitals in the local district and identify potential donors whose organs may be suitable for transplantation (Starzl 1992). Taylor’s contributions in the laboratories, as an organ procurement coordinator and as Starzl (1992) affectionately puts it, ‘jack of all trades’ lasted for twenty-nine years.

Together, Starzl, Taylor and their colleagues pushed the boundaries in their efforts to improve transplantation and the lives of those in end stage organ failure, as did other transplant teams around the world. All assisted in the development of many of the techniques, procedures and coordination practices in this area of medicine. Transplantation did not cure everyone but in the end these pioneers paved the way for today’s successes.

In a final word about his laboratory assistant and transplant coordinator at a reception in New Orleans in 1991, Starzl (1992) described Taylor as one who with grace and dignity overcame great prejudice to pave the way for future coordinators:

... Paul Taylor ... could be seen moving confidently through the New Orleans crowd, snapping photographs of old friends who were embracing and reminiscing. In his youth, he would not have been welcome in this room except as a servant. Greying now, he still carried in his head the names and fate of the earlier patients saved by the cadaver organs he had obtained. He also stayed in touch with the donor families long after the world had forgotten them. It was like a personal religion (Starzl 1992, p. 337).

It is evident that even in the formative years of organ donation and transplantation those intimately involved in the process were somehow bonded by it. This changed them forever and relationships were formed that would last a lifetime. Starzl makes this clear in the following extract from his book about the reception in New Orleans:

One after the other, those who were there spoke, each with their own memories and feelings. Once they had known each other as doctors, nurses, patients, parents and technicians. Through a mystical fusion, each had absorbed a part of the others and had become a puzzle person. They were friends now with no professional or cultural barriers (Starzl 1992, p. 337).

Taylor was very much a part of the puzzle people described by Starzl (1992). Coordinators continue to be puzzle people today. As organ donation and transplantation has advanced immeasurably, the human contact and involvement that coordinators have with donor families and recipients has continued to increase, making these health professionals a significant part of this life cycle.

Another of the earlier transplant coordinators is Donald Denny (Starzl 1992). Denny worked as a social worker prior to becoming a transplant coordinator in Philadelphia. He was then appointed the Director of the Transplant Organ Procurement Foundation (TOPF) in the early 1980s. Also noted as a key person involved in the TOPF was a nurse by the name of Mary Ann Palumbi (Starzl 1992). Palumbi was a very knowledgeable woman and her main role was to decide which potential recipients would receive cadaveric kidneys. She was also involved from time to time in organ procurement and was reported to be an excellent speaker and advocate for organ donation, given her knowledge of hospital systems and extensive intensive care experience (Starzl 1992). From

their humble beginnings transplant coordinators were both relatively autonomous and given significant responsibilities.

Transplant coordinator appointments coincided with the establishment of the first organ procurement organisations (OPOs), which continue to operate in the USA today. As the number of organs procured and transplanted increased, so did the need for transplant coordinators. Other countries followed the USA with the Netherlands and the United Kingdom appointing their first transplant coordinators in 1979 (Wight 1991; 1989), Spain in the mid-1980s (Matesanz & Miranda 1995*b*), Australia in 1983 (Fitzgerald & Martyn 1992) and New Zealand in 1987 (Maddison 1998).

Information regarding transplant coordinators, their appointments and roles is difficult to piece together as there has been no systematic recording of these historical events in the literature. It has come from isolated anecdotal articles written by those involved in the field. This information is, however, an important and significant part of transplant coordinators' history and for that reason has been included in spite of evident gaps in documentation.

### **Transplant coordinators in Australia and New Zealand**

The first Australian transplant coordinator was the late Elizabeth Yeo. She was appointed as a donor coordinator in 1983 and was based at the Australian Red Cross Blood Transfusion Service in Sydney, New South Wales (Herbertt 1995). Yeo looked to her transplant coordinator colleagues in overseas OPOs and transplant units for assistance in setting up the infrastructure, coordination systems and practices that led the way for others in the profession (Gordon 2004, pers. comm.; Fitzgerald & Martyn 1992).

Many of the practices she instigated throughout her coordination career continue today. For example she, like her counterparts in other countries, coordinated the organ retrieval process from the donor hospital's Intensive Care Unit and then went to theatre to assist with organ perfusion. She was also often the one who sought consent from the donor family. Follow-up letters to donor families, hospital staff and significant others together with data collection regarding each organ donor were also part of her routine practice (Gordon 2004, pers. comm.; Fitzgerald & Martyn 1992). Yeo was said to have been given a car, a couple of foam eskies, a beeper which she responded to twenty-four hours a day, seven days a week and was left to pioneer the role of transplant coordinator in Australia (Gordon 2004, pers. comm.). Elizabeth Yeo's considerable contribution and

legacy remains a guiding light for all Australian and New Zealand coordinators who participate in this challenging and rewarding profession.

The first Australian recipient coordinator, appointed in 1984 was Michael McBride and she was based in the Heart Transplant Unit at St Vincent's Hospital in Sydney. At the time kidney retrievals were performed in the donor hospitals, however, in the case of multi-organ procurement the donors in Sydney were transferred to St Vincent's Hospital for heart and kidney retrievals. This practice continued occasionally until 1986 (Fitzgerald & Martyn 1992). McBride (2005, pers. comm.) too tells of how tough the early days were when organ donors were transferred to the recipient hospital for cardiac retrieval and transplantation, in what was then seen as an amazing phenomenon, a miracle to most people. Moving donors to transplant centres is no longer practiced in Australia.

The first transplant coordinator in New Zealand was Carol Whitfield. She was employed as a recipient coordinator in September 1987 to work in the Cardiac Transplant Unit at Green Lane Hospital in Auckland (Whitfield 2004, pers. comm.). Like her counterparts in Australia she also was required to pioneer the role and be on call twenty-four hours a day, seven days a week. Initially, she coordinated heart transplants until approximately five years into her tenure when the unit began lung transplantation. Whitfield (2004, pers. comm.) was then responsible for the coordination of the transplant processes for both thoracic organs.

The first organ donor coordinator in New Zealand, Joanna Innes Walker (2004, pers. comm.) was employed on 1<sup>st</sup> December 1987 by the Auckland Hospital Board and was responsible to the Superintendent-in-Chief of the same Board. This position was established in conjunction with the Green Lane Cardiac Transplantation Program. Her initial brief was to facilitate the retrieval of hearts for transplantation and coordinate kidney retrievals at a regional level (Maddison 1998). Like her New Zealand and Australian colleagues before her, she was on call twenty-four hours a day, seven days a week and was also required to establish her role with minimal support.

### **Types of transplant coordinators and their role**

Transplant coordinators involved in solid organ donation and transplantation can be classified into two groups:

**Donor coordinators** (procurement) are primarily concerned with the organ donation process and donor family care. Broadly speaking they are responsible for the legal aspects of organ donation, family support, data collection, distribution of organs, organisation and coordination of retrieval teams, organ perfusion, packaging and shipment of organs and follow-up support to donor families and hospital staff. Hospital and community education is also the responsibility of the donor coordinator. They conduct death audits at the major donating hospitals to ascertain if potential donors were missed and maintain relevant databases. They are also involved in research and providing administrative support to facilitate organ donation (Shafer, Durand, Hueneke, Wolff, Davis, Ehrle, Van Buren, Orlowski, Reyes, Gruenenfelder & White 1998a; Shafer, Wood, Van Buren, Guerriero, Davis, Sullivan, Reyes, Levert-Cole & Oppermann 1998b; Maddison 1998).

**Recipient coordinators** (clinical) are primarily concerned with the transplantation process, recipient care and education prior to and at the time of transplantation. They are also responsible for recipient care and education in the longer term. They organise the transplant procedure and liaise with the donor coordinators and retrieval teams to ensure that the organ donation and transplantation procedures are coordinated and the organs are successfully retrieved and shipped to the appropriate hospitals to be transplanted into the recipients (McBride & Chapman 1995; Armstrong 1994).

### **Transplant coordinators' contributions**

The roles of both donor and recipient coordinators have developed and grown to contribute substantially to the field of organ donation and transplantation. Armstrong (1994) highlights the importance of transplant coordinators:

These vital roles link the entire process from donor to recipient referral, to retrieval and transplantation, and finally through to the long term post-operative follow-up. This coordination is vital to the successful outcomes now being achieved. They provide and maintain the structure that enables the system to function (Armstrong 1994, p. 2).

As transplant coordinator numbers increased and they began to network with each other, their influence and contribution to organ donation and transplantation became more apparent. This group of health care professionals began to explore what could be achieved if they worked together as a team. They investigated the possibility of organ sharing in an effort to maximise the supply of suitable organs for transplantation. These coordinators had established systems



of organ sharing nationally and internationally prior to the development of legislation to support such a practice in a number of countries, as was the case in Australia and New Zealand (Armstrong 1994).

They set up professional organisations for transplant coordinators and addressed the issue of education for those who practiced transplant coordination in order to increase their own knowledge and expertise. Finally they began establishing professional journals to assist with ongoing professional development, networking and educational opportunities for their members and allied health professionals (Elick 1997). Elick (1997) sums up their contribution:

Transplant coordinators have played a major and humane role in the medical miracle of transplantation. They have mandated sweeping as well as subtle changes and constantly refined their unique, diverse specialty. Moving from the role of assistant to facilitator, they have always championed a team spirit and kept the needs of patients uppermost. Coordinators have made profound contributions to legislation; education, research, and patient care (Elick 1997, p. 330).

## **Framework for the study**

Grounded theory is the overarching theoretical, philosophical and methodological framework used to conduct this study. Schreiber (2001) states that one of the strongest reasons for using grounded theory is when the researcher is investigating new or uncharted territory, as was the case in this study. The other reason for choosing grounded theory was that although it is uniquely suited to and often used in fieldwork and qualitative data analysis, it can easily be used with numerous other forms of data such as surveys, case studies and experimental design (Glaser 2002). Grounded theory transcends specific data collection methods and allows the researcher to combine and integrate any methods of data collection (Glaser 2002; 1978). This again was ideal, as the current study utilised both qualitative and quantitative data analysis to develop a substantive theory in the field of inquiry.

## **Significance of the study**

Following a review of the contemporary literature, it was evident that there was inadequate research on transplant coordinators and their practice. Apart from a few research articles that dealt with socio-demographic characteristics, a limited number on work practice issues and the culture of one OPO there was insufficient research on these health care professionals. This appeared to be even more problematic for the recipient coordinators who were identified very

infrequently in the research literature. The literature search also revealed that the participants in a number of the studies reviewed were not exclusively transplant coordinators. Study cohorts for example, consisted of all personnel employed by an OPO and not just the coordinators. This was a further indication that there was a need for research pertaining solely to this professional group and their practice.

This study provides an opportunity for Australian and New Zealand transplant coordinators to contribute to existing knowledge concerning transplant coordination, organ donation and transplantation. The provision of baseline data for future research, education and policy development is a further and highly significant feature of this investigation.

The research also highlights the complexities and diversity of the role. It generates data that may constructively assist with future curriculum development with respect to formal education, skills, knowledge and the psychological preparation required to facilitate best practices in this unique area of health care delivery.

## **Purpose of the study**

The purpose of this study was to identify and explore the issues and challenges that impact on transplant coordinators and their practice. This undertaking strives to facilitate a greater understanding of these health care professionals, their role and the contribution they make to organ donation and transplantation.

Objectives of the study were:

- to gain a better understanding of the issues and challenges that impact on transplant coordinators and their practice.
- to identify the professional needs of this group.
- to provide baseline data for future research, education and policy development.

The findings from this study add new knowledge to the literature in the form of a theory that identifies and extrapolates the issues and challenges that impact on transplant coordinators and their practice.

## Assumptions

Assumptions upon which the research was based were that:

- the role of the transplant coordinator is poorly understood in terms of its complexity and diversity. This may be due in part to the unique context within which transplant coordinators operate.
- there are significant issues and challenges for transplant coordinators, which impact on them and their practice.

## Outline of the thesis

**Chapter 1** - provides background information regarding transplant coordinators in order to set the scene for the study and gives an overview of the thesis.

**Chapter 2** - presents an in-depth review of the literature about transplant coordinators and consequently identifies and discusses the current knowledge regarding them and their practice. The review also highlights some of the problems and gaps in the existing knowledge, which further supports the purpose and objectives of this study.

**Chapter 3** - provides an overview of grounded theory, the theoretical, philosophical and methodological framework chosen for the study. An historical summary of the methodology is then presented followed by an examination of the components of grounded theory method: constant comparative analysis, substantive and theoretical coding, theoretical sampling, category saturation, memoing and theoretical sorting.

**Chapter 4** - presents a description of the methods used. It gives a detailed account of how the participants were recruited and the ethical considerations were addressed. A comprehensive description of the focus group interviews and Delphi survey questionnaires is also provided. Finally the issues of consensus, validity, reliability and triangulation are discussed.

**Chapter 5** - presents the first stage of the constant comparative analysis, which was the open coding of data from the recipient and donor coordinator focus group interviews.

**Chapter 6** - provides a detailed analysis of the statistical data obtained from the two Delphi survey questionnaires. Both descriptive and inferential statistics were carried out on the data using the Statistical Package for Social Sciences (SPSS).

**Chapter 7** - reports on how theoretical sampling from the Delphi survey questionnaires and the literature added to the codes, preliminary categories and categories, which had emerged from the data following, open coding.

**Chapter 8** - discusses how the categories, their properties and the links between categories were integrated. It also provides an explanation as to how the emergent theory was delimited. The fourth and final stage of the constant comparative method of analysis, the writing of the substantive theory, is then presented followed by the implications of the findings, the limitations of the study and recommendations for future research in the area.

# Chapter 2

## Literature review

### Introduction

This chapter presents an overview of the current literature relating to transplant coordinators and their practice. Two literature reviews were carried out. The first was a preliminary review undertaken in the initial stages of the research, with a second and more comprehensive review conducted towards the end of the study. This is common practice when using grounded theory methodology because the substantive theory generated in a study should emerge from the participants involved. It is therefore not necessary or recommended that a comprehensive critique or review of the literature be conducted at the beginning of a grounded theory study. Glaser and Strauss (1967) propose that the research data be dealt with first, as the literature may influence the researcher unduly and predispose them to forcing data into pre-existing codes and categories. This point of view is also confirmed by other exponents of grounded theory methodology (Heath 2006; Hickey 1997; Strauss & Corbin 1994). Glaser and Strauss (1967) do admit, however, that:

... no sociologist can possibly erase from his [sic] mind all the theory he [sic] knows before he [sic] begins his research. Indeed the trick is to line up what one takes as theoretically possible or probable with what one is finding in the field. Such existing sources of insights are to be cultivated, though not at the expense of insights generated by the qualitative research, which are still closer to the data (Glaser & Strauss 1967, p. 253).

In contrast, McCallin, (2003), Schreiber (2001) and Hutchinson (1993) argue that in order to identify the gaps in the literature it is necessary to undertake a review prior to the commencement of data collection and analysis in a grounded theory study. This suggestion is commendable as the most significant reason for undertaking research is to add new knowledge to a field of enquiry. Therefore, if a review is not undertaken it is difficult to know if there are deficits in the literature that warrant exploration. Smith and Biley (1997) offer a compromise in regard to these two polarised points of view:

General reading of the literature maybe carried out to obtain a feel for the issues at work in the subject area, and identify any gaps to be filled in using grounded theory ... but it is important that the reading is not too extensive (Smith & Biley 1997, p. 20).

Although they do not specify extensive reading or acknowledge prior learning or experience, this suggestion does enable the researcher to gain background knowledge of their topic. It is commonly acknowledged that researchers bring their belief systems, perceptions, ideas, theoretical frameworks and experience to their chosen area of enquiry which ultimately influence data collection and analysis (McCann & Clark 2003). Hence, whether or not the researcher begins to form ideas of potential codes and categories following a broad review of the literature, is a moot point and beyond the scope of this thesis. With this in mind, a preliminary literature review was undertaken to identify the gaps in the literature with a comprehensive one undertaken upon completion of data collection and analysis. The two reviews and critiques of the literature were then combined and are reported as one literature review in this chapter.

## **Parameters of the literature search**

An extensive and comprehensive search of the literature was undertaken in this study, the parameters of which are discussed below.

### **Aim of the review**

This review sought to critique and provide an overview of the available contemporary literature on transplant coordinators in order to identify possible issues and challenges that impact on these health care professionals and their practice.

### **Search criteria**

To be included in the review the articles or items had to meet the following criteria:

- Written and/or published between 1993 and 2005 inclusively. Normally a contemporary review would only include the literature from the past ten years. However, as there was an unpublished but relevant research paper relating to the Australasian coordinators written in 1993, the time frame for the review was extended by two years.
- Research articles - not anecdotal literature. Only research articles were included in the literature review for critique. Anecdotal literature, whilst interesting, is opinion and its value in terms of evidence is

debatable. Anecdotal literature has been included elsewhere in the study.

- Refer to solid organ transplant coordinators and/or their practice. Tissue coordinators were not included as their practice was outside the scope of this study.
- Written in English.

### **Key words/terms**

The key words, search terms or phrases used in the literature search were those commonly used in the area of organ donation and transplantation. Both Australian and American spelling and combinations of the two were used. An example of the search terms included transplant coordinator; transplant coordinator, organ donor coordinator, recipient coordinator, clinical coordinator and procurement coordinator. Further relevant search terms are listed in Appendix 1.

### **Definitions**

There were a number of definitions or descriptions in the literature defining transplant coordinators. However, in the context of this study a transplant coordinator was defined as a health care professional involved with any aspect of the coordination of the solid organ donation and/or transplantation process.

### **Sources**

#### **Electronic databases**

CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE, PUBMED (University of Adelaide Customised Version), COCHRANE LIBRARY, HEALTH SOURCE NURSING, EMERALD, EXPANDED ACADEMIC INDEX, MEDSCAPE (Nursing MedPulse), Academic Search Elite. Blackwell Synergy, Google Scholar and digital theses were searched for relevant articles on the research topic. Reference lists from the retrieved articles were then used to obtain additional literature. Only articles and abstracts that were in English were sought and included in the literature review due to time and financial constraints involved in translating research articles from non-English sources. Appendix 1 provides an audit trail showing the extensive research terms and other sources used in the literature search.

## **Literature in the field**

As stated, only research articles were included in the literature review for critique. In grounded theory methodology, literature is seen as a component part of the data and was therefore included in the constant comparative method of data analysis.

## **Transplant coordinator socio-demographic data**

There was limited research in the literature relating to transplant coordinators. What has been published focused on the socio-demographic profiles of these health care professionals. A number of researchers used surveys to gather socio-demographic information, while others addressed various aspects of the coordinators' role and work environment. Included in this group was the unpublished research by Jureidini (1993) a sociologist who surveyed members of the Australasian Transplant Coordinators' Association (ATCA) in 1993. Others used similar methods to gain insights into the profile and socio-demographic data of transplant coordinators. These included Wight (1994) who surveyed the European Transplant Coordinators' Organisation (ETCO) national key members in Western European countries. Roels and Kranenburg (1996) also conducted a survey of ETCO members three years after Wight's (1994) research. There had been such rapid growth in the numbers of transplant coordinators that they felt further investigation was warranted. In the United States, McBride (1995), Shafer (1994) and Vincent, Repper and Peters (2002) undertook similar research.

## **Division of the transplant coordinators' roles**

The advent of transplant coordinators was an evolutionary rather than a planned process. During the formative years, transplant coordinators were responsible for both organ donation and transplantation in many areas of the globe (Roels & Kranenburg 1996; McBride 1995). This changed as workloads increased and it became obvious that organ donation and transplantation should be managed as separate specialties. Elick (1997, p. 328) states that '... it became evident that separation of donor issues from recipient issues was ethically and politically justified.'

For some countries there was further specialisation, particularly in the USA, where the organ donor coordinator role was split into several areas of practice (McBride 1995). For example, some organ donor coordinators became designated requestors, who approached grieving families regarding organ



donation. Others were responsible for donor management in the ICUs and there were those who were involved in organ allocation or who assisted in theatre during organ retrieval.

In the transplantation speciality similar divisions of labour were also witnessed. Some recipient coordinators were assigned to the pre-transplantation care of potential recipients and others were responsible for the immediate and short-term post transplantation care. Longer-term care and hospital outpatient activities became the specialised area of practice for another group of recipient coordinators (McBride 1995). There was also specialisation in relation to specific organ systems: heart/lung, renal, pancreatic and liver, with most recipient coordinators practicing in a single type of transplant unit (McBride 1995).

### **Professional background**

Transplant coordinators come from varied professional backgrounds although in most countries a significant number are nurses (Gimbel, Strosberg & Lehrman 2001; Shafer 1994; Jureidini 1993). This was also the case in Vincent, Repper and Peters' (2002) study, which confirmed that 81% of respondents to their large survey of 1661 transplant coordinators from the North American Transplant Coordinators' Organization (NATCO) were nurses. However, there are several European countries such as Spain, France and Italy where the majority of the transplant coordinators are medical practitioners (Roels & Kranenburg 1996). This diversity accounts for some of the variation in qualifications and differences in work experience that are evident in the transplant coordinator population.

### **Age**

According to the literature the majority of transplant coordinators are in the 30 – 39 years age group (Roels & Kranenburg 1996; Shafer 1994; Wight 1994; Jureidini 1993). It is acknowledged that these studies were carried out some time ago but the current research confirms these findings in relation to the average age of transplant coordinators. Jureidini (1993) states that the findings in his research may in fact indicate that a level of maturity, previous responsible work experience and tertiary qualifications may be prerequisites for employment as a transplant coordinator.

It is appropriate to state that maturity is multifactorial and is not only related to chronological age, the attainment of qualifications and appropriate work experience. Other factors such as communication, leadership skills, personality

traits, and life experiences outside the work environment may also be significant indicators of maturity. Age, qualifications and work experience are part of the equation. Other equally significant factors may be the coordinators' ability to physically and psychologically perform the role in a manner that is both satisfying to them and effective in terms of the role itself.

### **Gender**

In some countries there was also a gender imbalance, for example Jureidini (1993) reports in his survey that the majority of participants were female. This is unsurprising as the majority of transplant coordinators are nurses and the nursing profession itself is predominantly female. Vincent, Repper and Peters (2002) also report that 92% of their study cohort were women. This was not the case in Roels and Kranenburg's (1996) study where 51% of participants were female and 49% were male. This may be explained by the fact that a percentage of participants in their study came from countries where medical officers are employed as transplant coordinators. There is possibly a more balanced ratio between males and females in the medical profession. Alternatively the majority of medical practitioners practicing as transplant coordinators are men, although there is no evidence in the literature to prove or disprove this theory.

### **Income**

Jureidini (1993) also makes the point that there was a significant income disparity in his study with male coordinators receiving a considerably higher income than their female counterparts. He does not offer an explanation for this disparity. There was also evidence in the literature of income disparity in relation to the educational background of the coordinators (Vincent, Repper & Peters 2002). This is not surprising as in Spain and other countries where many transplant coordinators are qualified medical practitioners, their salaries would be significantly higher than those with a nursing background. Similar pay disparity was demonstrated in Vincent, Repper and Peters' (2002) study where the more highly remunerated transplant coordinators were non-nurses with advanced degrees. They do not elaborate on the professional backgrounds of these participants. The other prerequisite for higher remuneration appeared to be extensive experience in the field. Those with higher incomes had been transplant coordinators for five years or longer with some having worked in the area for a decade or more (Vincent, Repper & Peters 2002).

## **Training and education**

Transplant coordinator training and education was also a focus of the surveys in the literature. Jureidini (1993) reports that approximately half of his participants indicated they had a training period. For most of them, however, this was one week in duration. Training that occurs over a one-week period may be more appropriately described as an orientation to the work environment. Wight (1994) asserts that training was a contentious issue but in the early 1980s transplant coordinators were able to attend courses in America. Later, ETCO conducted courses for coordinators. In more recent times individual countries have taken the responsibility of training local coordinators. Wight (1994) does not discuss the type or duration of training except to say that the American courses are certified.

Kranenburg and Roels (1997) in the second part of their survey of ETCO members, found that 99% of transplant coordinators agreed that there is a significant need for training courses. They also state that the training courses conducted by ETCO are flexible, as they can be run in a number of ways, with the advanced course being conducted over three to five days. Eighty-eight percent of participants felt that there was a need for a certified course for transplant coordinators and 49% of these respondents believed that certification would establish independent status for transplant coordinators (Kranenburg & Roels 1997). This significantly indicated that the participants wanted the role of transplant coordinators to be recognised as a profession in its own right.

Whilst these studies offer valuable information regarding the socio-demographic profiles of transplant coordinators and certain aspects of their role, there are limitations in each of them. The major limitation in Jureidini's (1993) study lies in his sample size as the number of coordinators in ATCA in 1993 was relatively small. This was further complicated by a response rate, which accounted for approximately half of the transplant coordinators in the study sample. Jureidini (1993) makes the point that with only 24 valid questionnaires being returned he was unable to generalise and it was also 'difficult to reveal certain results due to confidentiality. That is, to discuss the results of certain questions ran the risk of identifying individual respondents' (Jureidini 1993, p. 2). Another potential limitation is that the article reports on selected data from the survey of ATCA members without indication of what is excluded. With the non-reported data being unknown and unavailable to the researcher it is difficult to make a full and fair analysis of this research, its contribution and limitations.

In Wight's (1994) study a significant limitation was that the survey was sent to the ETCO National Key Members in all Western European countries and there were only 14 questionnaires returned. She does not stipulate how many questionnaires were initially distributed and thus what percentage of the sample these surveys accounted for. There was no definite indication as to whether these key members were actually transplant coordinators, although one would assume that they were as they were members of ETCO. What constitutes a key member of ETCO is also not clearly articulated in the study. The consequences of this are that the sample size of the study was limited and the data obtained from the respondents were the views of a select few key members.

The survey conducted by Roels and Kranenburg (1996) of ETCO members aimed to complement the earlier survey conducted by Wight (1994) and to identify what the transplant coordinators expected from ETCO. The sample size and those involved in the survey were much more clearly defined in Roels and Kranenburg's (1996) study. Although this survey was sent to a larger number of transplant coordinators (n = 176) the response rate was only 51%. The response in McBride's (1995) study consisted of 57% of participants. McBride (1995) also clearly defines her sample however, she does not elaborate on how her participants were recruited or how her data was analysed.

Vincent, Repper and Peters' (2002, p. 212) study purports that '... an informal 19 item survey was sent to 1661 transplant coordinators ...' No definitive explanation of an 'informal survey' is given. They do, however, state that the survey instrument was not piloted or validated in any way, as their intention was to communicate and seek information from 'coordinator to coordinator' (Vincent, Repper & Peters 2002, p. 213). They clearly articulate who is in their sample together with the objectives of their study. As with a number of the other surveys their response rate was poor with only 26% (n = 424) of their study cohort returning surveys. As the sample size was large, the issue of participant confidentiality was less problematic.

Whilst these basic surveys provided valuable information regarding the profiles of transplant coordinators and some aspects of their appointments, backgrounds, education and training in various parts of the globe, they offer little other information in relation to transplant coordinators and their practice. Except for Vincent, Repper and Peter's (2002) research, which was more comprehensive than the others and addressed most of the matters relating to method, there was no indication of whether the survey instruments in each of these studies had

been piloted prior to distribution to their study cohorts. Nor were there any explanations as to how participants were recruited, the sampling techniques used and how the qualitative data obtained in these studies, if any, was analysed. Finally, it is important to note that these studies, with the exception of that by Vincent, Repper and Peters (2002), were conducted some time ago and their relevance to transplant coordinators practice may be questionable.

## **Work practices**

The research papers that addressed some of the work practice issues for transplant coordinators are discussed below.

### **On call**

The patterns and effects of on call work on transplant coordinators in the United Kingdom were highlighted by Smithers (1995) who surveyed 61 participants with a response rate of 90%. Smithers (1995) in a self-administered survey found that 17% (n = 9) of the transplant coordinators had on call responsibilities virtually every day of the week. Other coordinators were required to be on call 1 in 2 days and 1 in 3 days. However, these coordinators too were routinely required to cover the on call commitments of their colleagues when they were absent for any number of reasons (Smithers 1995). On call referred to any time outside usual business hours therefore after 1700 hours and before 0900 hours Monday to Friday and during weekends (Smithers 1995).

The other aspect of the study was to identify and explore the perceived or actual effects of on call responsibilities on performance, absenteeism and health and wellbeing of the transplant coordinators (Smithers 1995). Smithers (1995) also discusses how on call can affect the participants' off call time. The main effects of on call responsibilities on health and performance as reported by the transplant coordinators (Smithers 1995) were:

- fatigue,
- a reduction in work performance,
- difficulties sleeping,
- poor diet,
- poor quality off call time.

On call commitments, which are a fundamental component of providing a 24-hour service, had a significant impact on the transplant coordinators' sense of wellbeing and work performance. This included feelings of tiredness, lethargy, a lack of concentration, stress, intolerance, inability to complete tasks and shortness of temper (Smithers 1995). Other transplant coordinators emphasised that it was not only being on call that caused angst, even the knowledge that they would be on call in the ensuing days caused tiredness as they became preoccupied with their pending on call commitments and felt an urgency to complete tasks (Smithers 1995).

On call obligations had a negative impact on the quality of the coordinators' off call time (Smithers 1995). Reasons for this included the need to catch up on sleep, the requirement to address home duties and feeling tired and unenthusiastic about attending social engagements. Some transplant coordinators disclosed relaxation problems - stating they had ongoing intrusive thoughts about work and feeling pressured to fill their days off with as many activities as possible before they were required to resume on call duties.

Recommendations made by Smithers (1995) were that the frequency of on call commitments for transplant coordinators should not exceed 1 day in 3 and under no circumstance should coordinators be expected to be on call every day. Another suggestion was to provide adequate prospective cover for holidays and other leave entitlements (Smithers 1995).

In addition, Smithers (1995) suggested that a partial shift system could be implemented in order to deal with the problem of excessive continuous working hours which transplant coordinators are often engaged in. Such would require the coordinator to hand over to a colleague during the organ donation process if the coordinator is an organ procurement coordinator or conversely hand over during the transplantation process if the coordinator is a recipient coordinator. This solution has some merit, however, instead of one coordinator being on call for 24 hours, in a system such as is recommended by Smithers (1995), the organisation would require two transplant coordinators to be on call for each 24 hour period. Therefore the on call requirements of the organisation would double.

In addressing one occupational health and safety issue, the organisation would be compounding another equally debilitating source of fatigue and chronic tiredness through an increase in on call commitments for all coordinators on staff.

This system would only work if there were significantly more coordinators employed by agencies and/or transplant units to cover the increases in on call commitments. The proposed system may also suffer if there was no 'slack in the system'. The capacity to increase on call commitments would be non-existent in situations where coordinators are already on call twenty-four hours a day, seven days a week. The other difficulty with this system is that even if the organ donation or transplantation process is split between coordinators, consecutive hours worked by each of the coordinators may remain significantly high and ultimately two coordinators may be exhausted following the process rather than one.

Smithers' (1995) study had both an adequate sample size to ensure the confidentiality of her participants and an excellent response rate of 90%. She also clearly articulated who was in her sample and how the participants were recruited. She describes the data collection instrument and how the accuracy of the questionnaire was assessed through peer review and piloting the survey. The difficulties experienced by many researchers as to what denotes an organ procurement coordinator and/or a recipient coordinator were also found to be problematic for Smithers (1995). She states that the distinctions made by others regarding the classification of coordinators were not absolute and she therefore decided not to divide the sample into two distinct groups, preferring to research the transplant coordination population as a whole (Smithers 1995, p. 470).

### **Transplant coordinators' work ethic and commitment**

Smithers (1995) also makes the point in her research that transplant coordinators have an excellent work ethic and commitment to their colleagues and the service they provide. This quality too was evident in other research papers as is indicated by Shafer (1994):

The foundation of the national organ procurement and transplantation system ... is built upon the dedication and effort of a unique group of health care professionals. These individuals are ... transplant coordinators (Shafer 1994 p. 6).

Vincent, Repper and Peters (2002) also identified a strong commitment from transplant coordinators to their profession, stating that a number of respondents appeared to have made a considerable commitment to the role which in some cases may be a life-long one:

... the diverse and complex tasks, the independent nature of the work, the varied responsibilities as well as the satisfaction of completing tasks

to a successful end nurture commitment in a way that is, perhaps, unique. In fact, coordinators may view their profession as clearly different from nursing, and the long-term commitment to this interesting vocation appears to be firm (Vincent, Repper & Peters 2002 p. 216).

In order for transplant coordinators to maintain that commitment and continue to deliver a high level of service it is vital that there is a balance between work commitments and private life. Smithers (1995) states that it is also essential that one aspect of the coordinators' role does not compromise the day-to-day work activities of the individuals who deliver this essential service. This is difficult to monitor due to the unpredictable nature of the transplant coordinators' work.

### **Recruitment and retention**

In their research titled 'Effects of quality of work life plan on employee recruitment and retention at Organ Recovery Systems, Inc.' (ORS), Haid, House, Kea, Hott, Wagner and Whisennand (1993) make the point that employee turnover rates are a serious problem for any health care environment. They also state that staff turnover in organ procurement organisations (OPOs) is particularly prevalent (Haid et al. 1993). A survey conducted by the Association of Organ Procurement Organisations in 1990 (cited in Haid et al. 1993, p. 19) supports this claim, stating that the average length of tenure for organ procurement coordinators is 2.1 years. This is problematic, not only for the coordinators themselves but also for the institutions that employ them, as it generates significant financial and operational costs (Haid et al. 1993).

The reasons for high attrition rates amongst transplant coordinators are not clearly articulated but are thought to be due to stress, unclear job expectations, long hours, on call and competition from other employers particularly in relation to nurses due to the current demand for their services (Haid et al. 1993). Taylor, McGaw, Mayes, Cossé and Weisenberger (1998, p. 89) report that coordinator attrition may be due to the effects of the role on the procurement coordinators' personal life, difficulties associated with death and dying, lack of acknowledgement and appreciation by other health providers, particularly those in the medical profession, sleep deprivation and anxiety related to being on call.

According to Haid et al. (1993) another reason consistently given in exit interviews and employee surveys conducted as part of their research was a lack of recognition. Whilst the authors acknowledged that there are factors that contribute to staff attrition rates that are beyond the control of management, they



believe there are a number of strategies that could increase job satisfaction levels (Haid et al. 1993).

In order to achieve more successful outcomes in terms of job satisfaction for employees they implemented a 'quality of work life' (QWL) plan. Strategies such as recognising employees' birthdays, creating the 'extra mile' award, a staff bulletin and introducing an employee appreciation week were all part of the QWL plan. The plan was based on the principle of employee recognition, which encouraged managers to acknowledge employees' value and accomplishments at every opportunity (Haid et al. 1993).

All employees at the participating OPOs were included in the study cohort, however, in spite of the stratified sampling much of the article refers to transplant coordinators and the reasons for their high attrition rates. This study is action research, although this is not clearly stated by the authors. All participating OPO staff were interviewed and then a QWL program was instigated with the aim of improving recruitment and retention rates for OPO employees. The effects of the QWL plan were then evaluated (Haid et al. 1993).

The limitations of this research are the stratified sample as the reasons coordinators choose and remain in this type of employment may be significantly different to other employees. The study sample is also not clearly articulated. There is a strong inference that the study cohort includes all personnel employed by the participating OPOs, not just the transplant coordinators. This is indicated in the research paper: 'All 83 individuals who were employed full-time during the period of study were included' (Haid et al. 1993, p. 19).

Shafer, Van Buren and Andrews (1999) postulate in their research that staff attrition rates are drastically reduced with leadership, organisational focus and an increase in the level and numbers of staff. This suggests that experience and advanced expertise may be of greater value to the organisation. This essentially was confirmed in the article which states that the qualities they looked for in a staff member were independent thinking, maturity, intelligence, professionalism and passion in relation to organ donation and the work environment (Shafer, Van Buren & Andrews 1999). The reasons Shafer, Van Buren and Andrews (1999, p. 44) gave for increasing the numbers of appropriate staff included:

- the ability for transplant coordinators to respond to a callout regarding a potential donor within one hour,

- to ensure adequate staff coverage,
- to enable an increased visibility within the hospital environment,
- to enable the flexibility for two transplant coordinators to attend when called to a hospital for a potential donor case,
- to ensure that transplant coordinators are able to spend adequate time with donor families to gain consent and answer questions,
- to decrease transplant coordinator attrition rates and in so doing increase the knowledge base of staff due to extended tenure.

Organisational commitments, intention to quit and job satisfaction are often cited as the traditional predictors of staff turnover (Bluedorn 1982). Gimbel, Strosberg and Lehrman (2001) however, in their ethnographic research of the culture of an OPO, found this was not the case. The staff in their research demonstrated a high level of job satisfaction and commitment to the organisation. The traditional factors put forward as strong indicators for staff attrition therefore offered little information with respect to why staff ceased their employment with the OPO under review (Gimbel, Strosberg & Lehrman 2001). What Gimbel, Strosberg and Lehrman (2001) discovered was that coordinators were more likely to resign from their positions due to the constant physiological and emotional stress they encountered on a daily basis.

Transplant coordinators are required to deal with death, grieving families, staff issues and extended working hours in their professional environment. There is usually no emotional support for the coordinators themselves and the physical and psychological stress they experience is often relentless (Gimbel, Strosberg & Lehrman 2001). Gimbel, Strosberg and Lehrman (2001) believe this is brought about by an inadequate support system within which coordinators are expected to operate whilst attempting to deal with these extraordinary stressors.

These views regarding coordinator attrition rates are not necessarily held and/or viewed negatively by all in the industry. In an article about the profile of the Spanish transplant coordinator by Matesanz and Miranda (1995a), they state that the average tenure of coordinators does not usually exceed four years with few rare exceptions. This they see as a positive factor as they believe the role is particularly difficult both physically and psychologically and changing staff regularly is deemed appropriate (Matesanz & Miranda 1995a). They also

emphasise that coordinators need to be very passionate and enthusiastic about the role and that when this drive begins to wane it is time to change regardless of tenure issues (Matesanz & Miranda 1995a). This is highlighted emphatically in the following statement: 'A passive attitude is always negative and should be banned' (Matesanz & Miranda 1995a, p. 2390).

In research conducted by Taylor et al. (1998) 69 executive directors from OPOs were surveyed in regard to transplant coordinator attrition figures, with a response rate of 51% (n = 35). Results of the survey suggested that attrition rates amongst organ procurement coordinators are not as common as is anecdotally reported (Taylor et al. 1998). Taylor et al.'s (1998) literature review was inconclusive and did not confirm or deny a problem with attrition rates amongst transplant coordinators, leading the researchers to assume that the perceived issue had more to do with transplant coordination folklore than empirical facts.

The researchers did, however, report that there was a concentration of attrition amongst transplant coordinators in the early phases of their employment. This they attributed to poor communication about the role and expectations of the position (Taylor et al. 1998). Other than the early stages of tenure, attrition rates were not overly problematic and did not appear to have a significant impact on the function or expenses of the OPOs (Taylor et al. 1998). This they speculated may be due to the 'survivor' type attitude of the transplant coordinators. Evidence of this was exhibited in the focus groups they conducted prior to survey distribution, where coordinators expressed a willingness to cope with whatever came along. When staff left they picked up their workload and carried on (Taylor et al. 1998) thus minimising the impact on the institution in regard to organisational activities and finances.

The study by Shafer, Van Buren and Andrews (1999) does not only address the issues that affect the transplant coordinators but is inclusive of the other staff members employed in the OPO. The research 'Program development and routine notification in a large, independent OPO: a 12-year review' does, however, offer some insights about the employment and retention of transplant coordinators. It is unclear if the data relating to the transplant coordinators comes from the coordinators themselves or are the views of others such as the executive directors, employed by the OPO.

The Taylor et al. (1998) study clearly articulates their sample of 69 executive directors who were surveyed in relation to the attrition rates of transplant coordinators. The transplant coordinators did participate along with executive directors, hospital personnel, managers and supervisors in the focus groups used to inform the development of the survey instrument in the study. There were several other limitations evident in this study, which are acknowledged by the researchers including the 51% response rate and the fact that the study referred to a retrospective three year period and therefore relied on the memory of the executive directors and the available documentation. The other problematic factor was that many executives involved in the study were not the same executives employed during the study period and this also may have led to some inaccuracies (Taylor et al. 1998, p. 92).

## **Culture of an organ procurement organisation**

An ethnographic study of the culture of an OPO in the USA by Gimbel, Strosberg and Lehrman (2001) found three well-established themes that had an impact on staff. Once again the study cohort was not exclusive to transplant coordinators with a stratified sample of 10 OPO employees, although much of the data presented appears to reflect the role and culture of the coordinators (Gimbel, Strosberg & Lehrman 2001). The following is a brief summary of the main themes identified in the study.

The first of these was the 'culture of coping and sharing' (Gimbel, Strosberg & Lehrman 2001, p. 250). Gimbel, Strosberg and Lehrman (2001) assert that transplant coordinators are exposed to a number of emotional and physical stressors in their role including being on call every day for potential donor referrals. They are often required to work exceptionally long hours with no support, relief, food or sleep. Gimbel, Strosberg and Lehrman (2001) state that transplant coordinators can work up to 30 consecutive hours if they are organising an organ donation. The combination of these factors together with counselling and supporting a distraught donor family can and does take its toll on transplant coordinators (Gimbel, Strosberg & Lehrman 2001).

For some coordinators crying is a welcome release, particularly if the donor was a paediatric patient and the coordinator has children of their own as is reflected by one participant in the Gimbel, Strosberg and Lehrman (2001) study:

It's a whole different ball of wax when you're [requesting donation] ... in a room with the family of a 10-year old or 14-year-old child – there is just

nothing sensible about [death]. I have children too, so the pediatric donors often hit awfully close to home. That's tough, that's extremely tough. I'll never get used to it, and if I do, there's a problem (Gimbel, Strosberg & Lehrman 2001 p. 251).

Other coordinators find solace in confiding in a colleague or a family member whilst others seek professional counselling or debriefing although this option was rarely utilised by the OPO employees studied in the research (Gimbel, Strosberg & Lehrman 2001). Another difficulty reported by the participants was that their work lives had a considerable impact on their personal lives with most acknowledging that they missed family gatherings or important personal functions due to work commitments (Gimbel, Strosberg & Lehrman 2001). The combination of these factors rather than job dissatisfaction led them to contemplate resignation or ultimately leave the profession (Gimbel, Strosberg & Lehrman 2001).

Also articulated in the research was the balance between teamwork and independence. Teamwork was reported to be an essential component with coordinators expected to make a substantial contribution to the work environment, be trained in all aspects of the role and also be available to assist others. However, they were also frequently required to operate autonomously particularly when organising the organ donation process. This was welcomed by the more experienced and longer serving transplant coordinators but was very distressing to the less experienced staff members (Gimbel, Strosberg & Lehrman 2001).

The second theme was a 'culture of conflicting priorities and uncertainty' (Gimbel, Strosberg & Lehrman 2001, p. 252). There were three areas of concern regarding this theme. The first was that on occasions transplant coordinators felt the needs of the organisation were not congruent with those of the donor family (Gimbel, Strosberg & Lehrman 2001). To set the scene – in the USA OPOs are required to reach minimum donor numbers to maintain funding for their facilities. This of course translates into performance pressures for transplant coordinators who must reach the required quotas. Difficulties arise when transplant coordinators believe that organ donation may not be the right course of action for a family. The coordinator is faced with the dilemma of who should take priority - the organisation that employs them and thus provides them with a livelihood, or the grieving donor family (Gimbel, Strosberg & Lehrman 2001).

The unpredictable hours were also problematic for transplant coordinators, leaving them feeling uncertain about when they would be able to follow through with other work projects and commitments (Gimbel, Strosberg & Lehrman 2001). The final area of uncertainty revealed in the research was that transplant coordinators are unsure as to what they might find when they are called upon to discuss organ donation with a potential donor family. Although considerable effort is made to find out about the family dynamics and their feelings about organ donation, ultimately transplant coordinators are entering unknown territory in regard to each family encounter (Gimbel, Strosberg & Lehrman 2001).

How will the family respond? Will there be anger, frustration, acceptance, endless questions or no questions at all? Are they all in agreement? Do they understand brain death? Do they want to talk about the person who has died or be left privately with their own thoughts? The variables are endless and each family and indeed each individual in the family are all different. Their responses to the tragic death of someone they love and the possibility of organ donation will be unique to each of them. Transplant coordinators must therefore be prepared to deal with the unexpected, they must be flexible and willing to confront whatever they are presented with.

Transplant coordinators need to be non-judgemental, caring and compassionate as the interaction the family has with the coordinator will be likely to remain with the family forever. The family may not remember what was said or who said it but they will remember how the transplant coordinator made them feel. Regardless of the outcome in relation to the consent, what is crucial is that transplant coordinators only get one chance at this interaction and it needs to be appropriate.

The final theme discussed in the paper was the 'culture of mission and reward' (Gimbel, Strosberg & Lehrman 2001, p. 252). Reference was made to the reasons why transplant coordinators remain in the role despite the obvious difficulties and stresses it entails. Gimbel, Strosberg and Lehrman (2001) discovered that the coordinators were driven by a strong ideological belief in organ donation and a desire to help their fellow human beings. It seems the intrinsic rewards were the most appealing aspects of the role for this group of health professionals. The stated enabling factors included recognition, the opportunity to make a difference, the work itself, the autonomy and the responsibilities of the role (Gimbel, Strosberg & Lehrman 2001). Vincent, Repper and Peters' (2002) study, which largely focused on recipient coordinators, also

identified professional autonomy, contact with patients and the team approach involved in transplantation as contributing factors in the level of job satisfaction experienced by coordinators. Vincent, Repper and Peters (2002) give an example:

Transplant coordinators appear to share several traits, which include elements of strong self-motivation and willingness to take on responsibility. Mastery of a diverse number of tasks with appropriate patient-related responsibilities clearly affirms that people in this field not only appreciate autonomy, but also require it in order to accomplish job tasks. The value placed on these particular matters may also further confirm that coordinators view themselves as professionals fully capable of managing complex medical circumstances in an independent fashion (Vincent, Repper & Peters 2002, p. 216).

Extrinsic factors such as supervision, work conditions and salary were observed to be secondary considerations as to whether a transplant coordinator would continue in their role (Gimbel, Strosberg & Lehrman 2001). Vincent, Repper and Peters (2002) highlighted similar factors as secondary considerations in their study and these included on call responsibilities, the level of remuneration, extensive working hours and paperwork. Taylor et al. (1998) present several other reasons as to why coordinators are drawn to the role and continue in it:

Motivation for taking a job as a procurement coordinator centered on the opportunity to develop marketable skills as well as the excitement and challenges of facing such a difficult job. "Adrenaline rush" and camaraderie have been cited as reasons for staying in the position (Taylor et al. 1998, p. 89).

The other motivating force highlighted in the research was the feedback received from donor families and recipients. Transplant coordinators converted these unique stories of humanity and success and they were certainly seen as a positive and fulfilling aspect of the role (Gimbel, Strosberg & Lehrman 2001). Another sustaining feature of the position was the coordinators' belief that lives would be lost if they did not give their best. Thus there was a great sense of purpose and mission (Gimbel, Strosberg & Lehrman 2001).

The final and perhaps ultimate reward for transplant coordinators was acknowledgement and praise from management for performance. This recognition was valued more if it came from managerial staff who had themselves been coordinators and therefore knew the dedication and sacrifices the transplant coordinators made in order to make a difference in their chosen careers (Gimbel, Strosberg & Lehrman 2001). Lack of recognition or infrequent and inconsistent acknowledgement from superiors was seen by a number of

coordinators as one of the most disappointing aspects of the role (Gimbel, Strosberg & Lehrman 2001).

The limitations of this study by Gimbel, Strosberg and Lehrman (2001) were that it only referred to one OPO; the sample was a stratified one and therefore addressed the culture of all employees of the OPO. There also appears to be a combination of methodologies used in the research:

In keeping with grounded theory tradition in ethnography, as presented by Strauss and Corbin<sup>4</sup>, an open coding process was applied to interviews transcripts using HyperRESEARCH version 2.0 software (Gimbel, Strosberg & Lehrman 2001, p. 250).

These two methodologies were not clearly defined and there was no information regarding how they would be used and/or combined in the study.

## **Summary**

This chapter began with an explanation as to why two separate literature reviews are required when using grounded theory methodology. The parameters of the literature searches were also outlined. This was then followed with a discussion and critique of the contemporary literature relating to transplant coordinators and their practice. From the literature it is clear there is a paucity of research on these health care providers with further research warranted.

Although there was limited research in the literature, the review did highlight some significant points; these being that transplant coordinators have demanding jobs with considerable responsibilities, work long and unpredictable hours and cope with incredible stressors. Stressors are also often dealt with in isolation with little or no support. The gap in the literature needs addressing to enable transplant coordinators to have a voice about their role, how they practice and the difficulties and challenges they face as they facilitate the process of solid organ donation and transplantation. This is a process that has already been identified earlier as one that impacts on many. This thesis aims to explore the role of the health care professionals known as transplant coordinators, the individuals who collectively facilitate a miracle of modern medicine. The following chapter discusses grounded theory - the methodology used to conduct this research.



# Chapter 3

## Methodology

### Introduction

This chapter provides an overview of grounded theory, the methodology chosen as the theoretical framework for this study. It begins with a discussion of the paradigm, the philosophical underpinnings, including the ontological, epistemological and theoretical perspectives that have influenced this methodology. An overview of the development of grounded theory is provided. Classical grounded theory as formulated by Glaser and Strauss (1967) is then presented outlining its techniques and methods and the reasons why the methodology was chosen for this research. The chapter concludes with a discussion about mixed methods of data collection as both qualitative and quantitative data were collected in the study.

### Research paradigms

There is much debate and conflicting terminology in relation to research paradigms, ontology, epistemology and methodologies. Evidence of this is seen in the literature with considerable overlapping of these areas and in a number of cases conflicting advice, all of which can be challenging and frustrating for the novice researcher. A paradigm refers to the basic belief systems, the metaphysics, or a view of the world that guides the choice of methods as they relate to the underlying ontology and epistemology of that view (Denzin & Lincoln 1998). It is a global term that encompasses the ontological, epistemological and methodological premises that guide research (Guba 1990). Guba (1990, p. 17) suggests that a paradigm is an 'interpretive framework' or a 'basic set of beliefs that guides action'. Sandelowski (2000, p. 247) states that '... paradigms of inquiry are best understood as viewing positions: ways, and places from which, to see.' Denzin and Lincoln (1994) emphasise that the underlying principles of a paradigm, although accepted as true, are unable to be proven.

According to Denzin and Lincoln (2000, p. 157) a paradigm should encompass four concepts: **ontology** – the nature of reality; **epistemology** – the nature of knowledge; **methodology** – the theoretical framework; and **axiology** – the ethical considerations. The first three concepts are examined below and the

axiology or the ethical considerations for the research are discussed in the following chapter. Crotty (1998) gives an overview of research paradigms and their philosophical underpinnings as shown in Table 3.1 below. This is one of a number of perspectives represented in the literature. It is the basic overview that was used in this thesis with the shaded areas indicating the applicable aspects of the paradigm.

**Table 3.1: Overview of paradigms**

NOTE: This figure is included on page 34 of the print copy of the thesis held in the University of Adelaide Library.

Reproduced from Crotty, 1998, p.5

## **Ontology**

One aspect of the research paradigm not reflected in the table is ontology, the nature of reality. According to Crotty (1998) ontology would sit parallel to epistemology, as he believes that both ontological and epistemological issues tend to emerge together and are thus inextricably linked. Crotty (1998) suggests that ontological issues can be dealt with as they emerge and it is unnecessary to include in a separate schematic representation or discussion. The researcher, however, needs to be distinct about the ontological perspective they intend to use.

Relativism, which is the ontological perspective chosen for this study, consists of multiple intangible realities that are mental constructions, which are experientially

and socially based. These realities are also local and specific in nature and are dependent on the individuals or groups that hold these constructions (Denzin & Lincoln, 1998, p. 206). Denzin and Lincoln (1998, p. 206) also assert that the construction of realities are more or less informed or sophisticated. This indicates that as individual or group knowledge increases so do the intricacies of their realities.

According to Crookes and Davies (1998) ontology is the most abstract concept within the research paradigm as it is concerned with the nature of reality itself. They succinctly describe ontology as follows:

The central issue is whether reality is perceived as something which is fixed and external or whether reality is shaped and influenced by how people interpret and interact with their world (Crookes & Davies 1998, p. 4).

This evaluation of ontology demonstrates how ontological and epistemological boundaries can be seamless and at times overlap as will also become evident in the following discussion.

## **Epistemology**

Constructionism is the epistemology identified in most theoretical perspectives with an exception being for the paradigms representing positivism or post-positivism (Crotty 1998). The naturalistic, phenomenological and interpretive research paradigms appear to be located within the constructionism paradigm and usually utilise qualitative data. However, paradigms within constructionism can include quantitative data as is used in this research. The combining of qualitative and quantitative data and data collection methods will be addressed later.

Epistemology is based on how reality and images of the world are conceptualised (Denzin & Lincoln 1998). It is therefore important that the epistemological stance adopted for any research undertaking is made explicit from the outset (Crotty 1998). For example, objectivist epistemology contends that meaningful reality exists regardless of whether or not there is anyone available to consciously acknowledge the object (Crotty 1998). An example of this perspective would be - a rock is a rock even if no one is aware of its existence. The object itself has inherent meaning. Constructionism rejects this notion of human knowledge, asserting that meaning is conditional upon the interaction with the realities of our world (Crotty 1998). There is no meaning if there is no conscious engagement -

meaning is constructed and not discovered. This view of constructionism is simply explained:

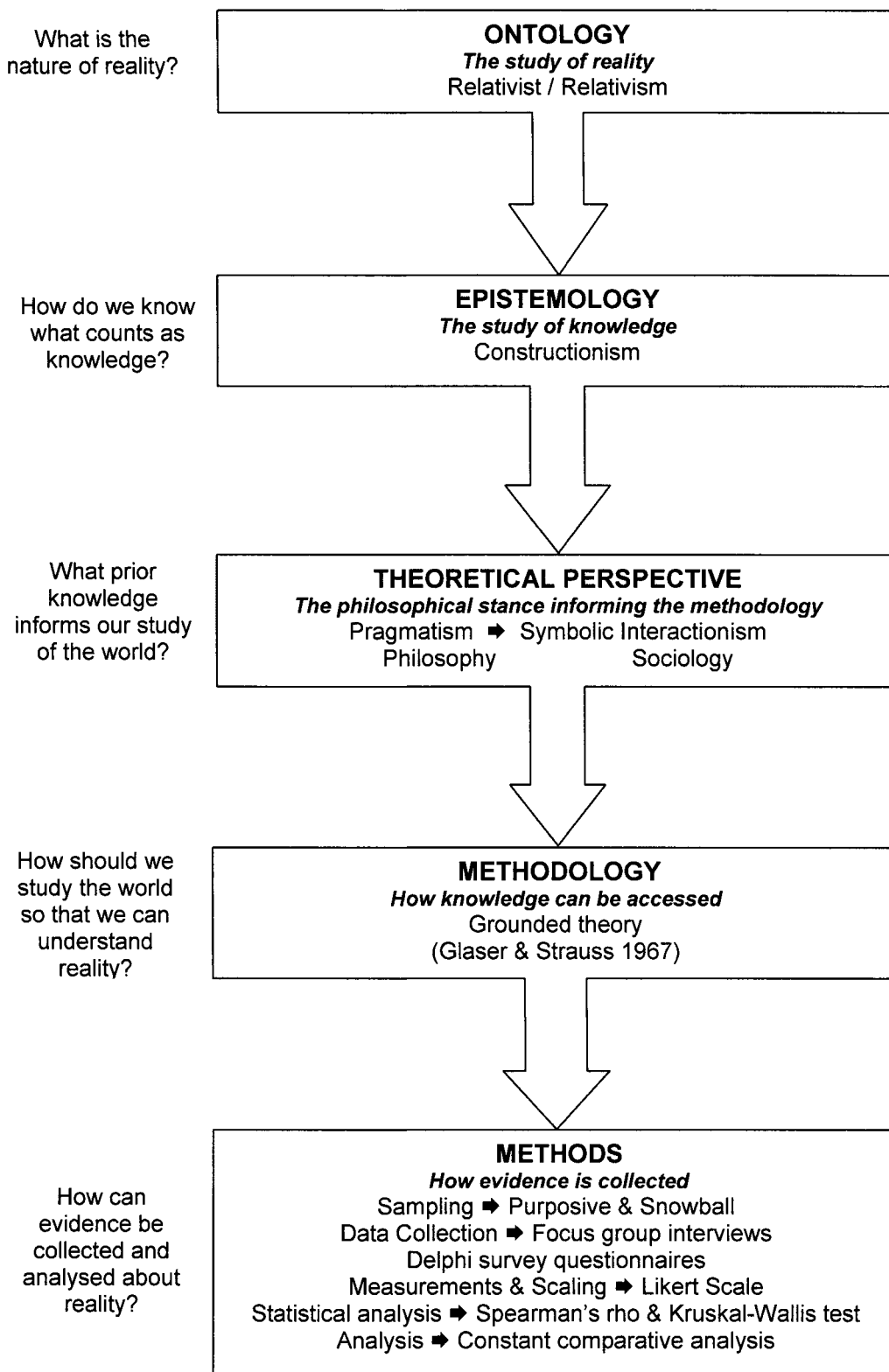
What the 'commonsense' view commends to us is that the tree standing before us is a tree. It has all the meaning we ascribe to a tree. It would be a tree, with that same meaning, whether anyone knew of its existence or not. We need to remind ourselves here that it is human beings who have construed it as a tree, given it the name, and attributed to it the associations we make with trees. It may help if we recall the extent to which those associations differ even within the same overall culture. 'Tree' is likely to bear quite different connotations in a logging town, an artists' settlement and a treeless slum (Crotty 1998, p. 43).

This research is based on the second epistemological perspective - constructionism, whereby reality is created when an individual interacts with their environment. It must be noted here that the realities of a particular phenomenon or experience are not carbon copies of each other as individuals are influenced and guided by a number of different factors including culture, prior learning, creative abilities, knowledge and experience (Crotty 1998).

### **Theoretical perspective**

There are a variety of theoretical perspectives that inform research such as positivism and post-positivism, which emanate from scientific or empirical inquiry. Other authors' perspectives such as critical theory, postmodernism, feminism and interpretivism are engaged when research using qualitative methods is undertaken. Two of these, which are a subset of the interpretive paradigm, are pertinent to the current study. They include symbolic interactionism from sociology and pragmatism from philosophy (Crotty 1998; Huber 1978). These two theoretical perspectives are viewed as parallel, as shown in Figure 3.1, although symbolic interactionism is said to have its roots in pragmatism (Blumer 1969; Glaser & Strauss 1967; Mead 1934/1967). Figure 3.1 also shows a schematic representation of the independent aspects of the research paradigm used in the study. The basic concepts of pragmatic philosophy as reported by Pursley-Crotteau, McGuire Bunting and Burke Draucker (2001, p. 193) are:

1. Truth does not exist 'out there' in the real world but is actively created as humans act toward the world;
2. People base their knowledge of the world on what has proven useful to them;
3. People define the social and physical objects they encounter in the world according to the way they can use them; and
4. If we want to understand people, we must understand what those people do in the world and how they interpret that world (Ritzer 1983).



**Figure 3.1: A schematic representation of interdependent aspects of the research paradigm used in this study**

Symbolic interactionism is a social-psychological theory that attempts to explain human behaviour. Its main focus is on human groups and human conduct (Patton 2002; de Laine 1997; Blumer 1969). A number of scholars have contributed to the development of symbolic interactionism including John Dewey, W.I. Thomas, Robert E. Park, William James, Charles Horton Cooley, Florian Znaniecki, James Mark Baldwin, Robert Redfield and Louis Wirth (Blumer 1969). A further two have been credited with making significant contributions to this theory. The first - George Herbert Mead, a social psychologist - put forward the notion that it was a human being's ability to have a concept of self that enabled them to be social beings who made sense of the world through social interactions (Mead 1934). He also said that the concept of self is learned in childhood through social interactions and by the roles and games children participate in (Chenitz & Swanson 1986).

The other main contributor was Herbert Blumer (1969) who considered that symbolic interactionism was based on three basic premises, namely:

... that human beings act toward things on the basis of the meanings that the things have for them.

... that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows.

... that these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he [sic] encounters (Blumer 1969, p. 2).

In symbolic interactionism, self is defined by the social roles one is involved in. It is these roles that enable individuals to experience and understand their world. Social interaction and life is experienced by symbols and the meanings that are attached to them (Bogdan & Biklen 2003; Blumer 1969). A person is not just a scholar or an athlete but also a son or a daughter, a friend, a confidant, a mother, a father, a musician, a nurse or an engineer, and no matter what roles that person participates in, it will shape who they are and how they interact in their social world.

## **Methodology**

Grounded theory embraces the interpretive traditions of symbolic interactionism and also offers a systematic research approach to investigate human behaviour and social interaction. This is achieved by utilising the main elements of symbolic interactionism and its epistemological underpinnings (Schreiber & Stern 2001).

## **Overview of the development of grounded theory**

Grounded theory was originally developed in the 1960s by two prominent sociologists - Barney G. Glaser and Anselm L. Strauss. Glaser worked at Columbia University and was a well-known researcher who engaged in quantitative methods of inquiry. Strauss was from the School of Pragmatism at the University of Chicago and specialised in qualitative methods of research (Stern & Covan 2001; Glaser & Strauss 1967). Both men were dissatisfied with the direction of their disciplines and the methodologies used in their respective areas of research - believing that there was an ever-widening gap between theory and research. They believed that too much emphasis was being placed on verifying existing theory rather than encouraging the generation of new theory (Glaser & Strauss 1967).

During his time at the University of Chicago the philosophies of symbolic interactionism and pragmatism influenced Anselm Strauss. The work of John Dewey, Robert E. Parks, Everett Hughes, G. H. Mead, W. I. Thomas and Herbert Blumer had a significant impact on his thinking and career path (Eaves 2001). It was Herbert Blumer (1969) who advised Strauss to enrol in a course on social interactionism developed by George Herbert Mead (1934/1967). Although Mead had died several years earlier, the University of Chicago course still bore his name indicating that he continued to be held in high esteem by the university. At this time Strauss continued his study into the philosophy of symbolic interactionism (Schreiber & Stern 2001). The influence of these scholars and the academic education Strauss received is evident in his contribution to grounded theory, the philosophical underpinnings of which come from symbolic interactionism (Schreiber & Stern 2001).

In contrast, Paul Lazarsfeld who was considered an expert in the field of quantitative research methods was the main influence on Glaser who received his education at Columbia University (Eaves 2001; Stern & Covan 2001). Although Glaser had previously participated in research using qualitative data he believed there was a need for more explicit and systematic ways of coding and generating theoretical hypotheses in research using qualitative methods (Strauss & Corbin 1990). Glaser's education influenced his contribution to grounded theory, whereby he integrated quantitative methods into the methodology as well as establishing explicit and systematic mechanisms for coding and hypothesis generation.

In the early 1960s these two scholars met at the University of California – San Francisco in the School of Nursing (Stern & Covan 2001). Anselm Strauss had been recruited to the university to add a level of scientific and theoretical input into the newly developed doctoral program for nurses (Stern & Covan 2001). Strauss welcomed the opportunity to study and build his own program in medical sociology using symbolic interactionism and pragmatism and set about recruiting other sociologists, one of whom was Barney Glaser, with similar interests to support his program (Stern & Covan 2001). He also believed that working within a school of nursing would have distinct advantages.

Strauss was happy to be working with nurses as he could see the potential of associating with professionals who had a significant amount of direct contact with patients (Schreiber & Stern 2001). During their time at the University of California, Glaser and Strauss secured funding for a study into dying patients. Their classic work *Awareness of Dying* (1965) discovered that there was considerable deception operating in hospitals with regard to the dying process. The study had a significant impact at the time on how death was dealt with by nursing and medical staff in the hospital setting. It was during this study that Glaser and Strauss became aware that the methodology they used was original. In keeping with Strauss' background they maintained the philosophy of symbolic interactionism and with Glaser's knowledge and quantitative expertise set about adding a systematic approach to data analysis. This marked the beginning of classical grounded theory methodology (Schreiber & Stern 2001).

## **Grounded theory**

Grounded theory is an inductive qualitative approach to research that was developed to study social phenomena from the perspective of symbolic interactionism (Glaser 2002; Glaser & Strauss 1967). It is concerned with human behaviour and how people manage problematic situations in their lives. The research process involves systematic data collection and analysis that enables the development of a theory derived directly from the research data (Glaser & Strauss 1967). Observational field notes and interviews are the main sources of data collection. Other methods such as quantitative surveys, journals, books, videos, photographs and informal meetings with participants, have also been successfully integrated (Schreiber & Stern 2001; Glaser 1978; Glaser & Strauss 1967).



The generation of theory using this methodology is an evolutionary process that occurs as the research is being conducted. It is based on constant comparative analysis among or between groups of people or participants in the area of research interest (Glaser & Strauss 1967). Grounded theory enables the identification and exploration of patterns and the relationships between patterns within the social phenomenon being studied (Glaser 2002; 1978; Glaser & Strauss 1967). It provides a method for the theoretical formulation, testing, development and redevelopment of a set of conceptual hypotheses about a substantive area of research (Glaser 1992; Glaser & Strauss 1967). It does not focus on single units; it is the study of abstract problems and the processes occurring within that social framework (Glaser 1992). Grounded theory facilitates the formulation and development of a conceptual theory that is grounded in the data to explain how participants in a social context process their main concern or problem (Glaser 2002; 1992).

Grounded theory is a combination of both inductive and deductive approaches (Heath & Cowley 2004). The primary approach is inductive as the researcher is continually guided by the data and its subsequent patterns, codes and categories in order to identify the emerging substantive theory (Glaser & Holton 2004; Glaser 1992). The goal of the methodology is to discover theory by allowing ideas to emerge from the data. Deduction is also used in grounded theory to verify and elaborate on the codes and categories as they emerge during each incremental step of theory development. This is not to be confused with verification of the theory as a whole, which is an entirely separate methodology and unconnected to grounded theory (Schreiber & Stern 2001; Glaser 1978).

The aim of grounded theory is to generate a systematic research approach for the development of a theory that explains the patterns of behaviour or the main concern of the study participants that is grounded in the research data (Kennedy & Lingard 2006; Glaser 2002; Eaves 2001; Chenitz & Swanson 1986). Glaser (1978, p. 93) confirms this in the following extract '... the goal of grounded theory is to generate a theory that accounts for a pattern of behaviour, which is relevant and problematic to those involved.' These patterns of behaviour are sometimes referred to as a basic social process (BSP), which will be discussed later (Glaser 1978).

Grounded theory is also a flexible and adaptable methodology as it can be used to develop both substantive and formal theory. Substantive theory is developed from research conducted in one specific area or contextual situation (Glaser &

Strauss 1967). For example, this research is based around the issues and challenges that impact on transplant coordinators and their practice. Formal theory development is more conceptual. An example of this would be research into pain or violence (Glaser & Strauss 1967). Substantive theories can be used as a basis upon which to build formal theories (Glaser & Strauss 1967).

## **Modifications to grounded theory**

The successful scholarly relationship between Glaser and Strauss led to the publication in 1967 of their seminal work on grounded theory, *The Discovery of Grounded Theory: Strategies for Qualitative Research*. They also went on to conduct many collaborative research projects together including *Time for Dying* (1967), *Anguish: Case Study of a Dying Patient* (1970), *Status Passage* (1971) and *Chronic Illness and the Quality of Life* (1975). Barney Glaser also published *Advances in the Methodology of Grounded Theory - Theoretical Sensitivity* (1978) (Glaser 1992).

However, in the early 1990s the relationship between Strauss and Glaser became strained when Strauss and Corbin's book, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* was published in 1990. Glaser inferred that Strauss and Corbin's methodology had moved so far from the original concepts that it could no longer be considered grounded theory (Glaser 1992). Glaser was deeply disturbed by Strauss' refusal to address this matter. Following several written attempts to persuade him to remove the text from publication and correct the numerous discrepancies he believed were evident in the book, he set about correcting them himself in his publication *Basics of Grounded Theory Analysis: Emergence vs. Forcing* (Glaser 1992). In this book Glaser (1992) levels numerous criticisms at Strauss and Corbin's grounded theory methodology, the major points of which are discussed below.

## **The theoretical basis of grounded theory**

Glaser believes that Strauss and Corbin do not adequately articulate if symbolic interactionism is the philosophical basis for their version of grounded theory methodology. He believes they fail to address this aspect of their work at all, stating that their method of conceptual description is without a methodology. He suggests they do not deliver a theoretical framework for their method and this leads to research that is too general and data that is forced and without relevance (Glaser 1992).

## **Emergence versus forcing of data**

Glaser (1992) purports that their methodology leads to forced description and not emergent theory as is evident in classical grounded theory. He is critical of the methodology's inability to contribute to more general levels of scientific enquiry, believing that the pure descriptive nature of the methodology makes it situation-specific, failing to add to substantive theories in other areas of research interest or contribute to a formal theory (Glaser 1992). Glaser (1992) asserts that grounded theory should be modifiable to all aspects of a given problem regardless of whether the problem is in the substantive area of research or in a new area of interest.

Glaser (1992) is also adamant that grounded theory is not about the verification of facts, which he argues is a different methodology altogether. He asserts it is the production of conceptual hypotheses and their integration, which leads to a substantive theory that is grounded and transferable (Glaser 2002; Glaser 1992). His concern is that Strauss and Corbin force their paradigm on the research by using a model to link properties and categories in the data rather than letting the theoretical codes and categories emerge. Their use of '... a coding paradigm involving conditions, context, action/interactional strategies and consequences' (Strauss & Corbin 1990, p. 96) ultimately leads to the development of hypotheses for verification rather than theory development. Glaser believes that Strauss and Corbin are not interested in inductive research and the emergence of theory from the data but are driven by their desire to test theory. That is not the purpose of classical grounded theory (Glaser 1992). The debate over forcing versus emergence of theory is one that is continually referred to by Glaser (1992) in *Basics of Grounded Theory Analysis: Emergence vs Forcing*. He is adamant that grounded theory is not about forcing preconceived ideas from data but rather patiently and systematically allowing the discovery of concepts and models as the study evolves (Glaser 1992).

## **Terminology usage**

Glaser (1992) also considers that Strauss and Corbin have changed some of the methods and terminology of original grounded theory without explanation or acknowledgement. An example of this is their use of axial coding which Glaser believes is another way of describing theoretical coding, an original component of Glaser and Strauss' grounded theory (Glaser & Strauss 1967).

Strauss and Corbin (1990) also discuss transitional system, conditional matrix and conditional path, concepts that Glaser (1992) believes are both complex and redundant. He argues that they are in direct opposition to the original tenets of grounded theory because they force theory rather than letting it emerge from the data (Glaser 1992). It is Strauss and Corbin's (1990) use of terms such as code notes (a type of memoing), dimensions and dimensionalising and the referring to the location of properties of categories along a continuum, that is the cause of great angst for Glaser (1992). He believes that these terms only add complexity to the methodology and are therefore unnecessary (Glaser 1992).

### **The use of quantitative and qualitative data**

Another crucial difference in Strauss and Corbin's (1990) methodology is their belief that quantitative data is only useful for verification purposes. This is in direct contrast to the tenets of original grounded theory in which both quantitative and qualitative data are deemed acceptable for the generation of theory. Glaser and Strauss (1967) state that the generation of theory is independent of the type of data used. They do not differentiate between data types believing that each has a place in theory generation and development (Glaser & Strauss 1967). Although grounded theory has become a methodology that often uses qualitative data, Glaser (1992) does not limit it in that way. He states that grounded theory was partially developed by him using quantitative data methods and it is a general methodology that can be used on any data or combination of data (Glaser 1992; Glaser & Strauss 1967).

### **Ownership and academic acknowledgement**

At the centre of this very public debate is Glaser's (1992) belief that Strauss and Corbin failed to acknowledge the intellectual property and contribution Glaser himself made to grounded theory. Glaser's distress regarding Strauss and Corbin's publication is evident:

Three books had been written beforehand using a multitude of ideas, concepts, and research directives. Basics of Qualitative Research sets forth methods with no scholarship reference to what has already been written, and it sets forth no description of the developments and changes that account for the new concepts, terms criteria, etc that are written for grounded theory in Basics of Qualitative Research (Glaser 1992, p. 5).

Glaser (1992) considers that Strauss and Corbin's book was written without conscience. Although Anselm Strauss did not deny Barney Glaser's co-authorship in the original grounded theory, he failed to acknowledge Glaser's

intellectual input and expertise and thus the significant contribution of his once good friend and colleague.

This debate will undoubtedly be an ongoing feature in discussions regarding grounded theory methodology, albeit not between Glaser and Strauss as Strauss is now deceased. It is a rueful conclusion to a relationship that offered and continues to offer much to the academic world. However, ongoing debate and constructive criticism may add to grounded theory methodology and its ongoing development, as it forces the consumers to distinguish their own beliefs and intentions.

Finally, Strauss and Corbin dedicated their book *Basics of Qualitative Research – Grounded Theory Procedures and Techniques* (1990) to Barney Glaser - with admiration and appreciation. Is this an acknowledgement of his contribution to grounded theory or a superficial means of placating their dissatisfied and disgruntled colleague Barney Glaser?

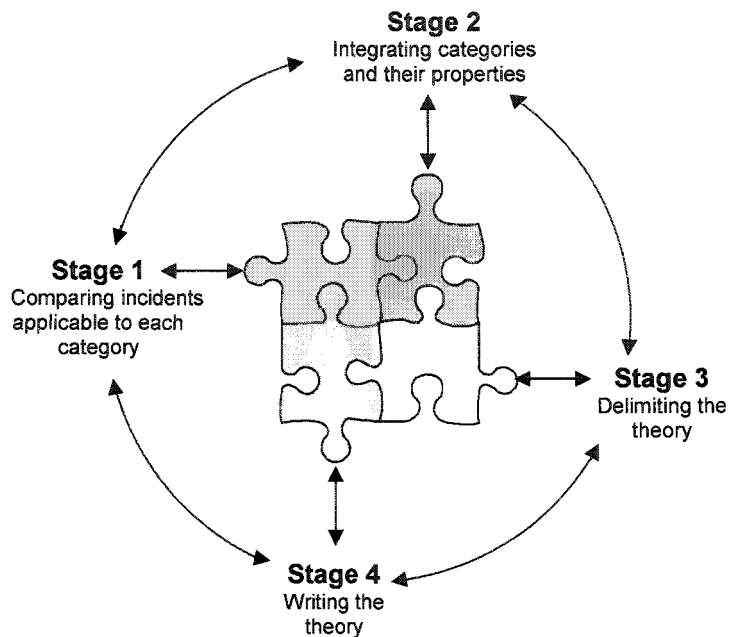
## **Grounded theory method**

Not only does grounded theory offer researchers a methodology with philosophical direction for substantive and formal theory development, but it also puts forward a method that assists the researcher in all aspects of data collection, analysis and the writing of their theory (Glaser 2002). Described below are the techniques of grounded theory, which were discussed by Glaser and Strauss in *The Discovery of Grounded Theory: Strategies for Qualitative Research* (1967) and further developed in Glaser's second book *Advances of the Methodology of Grounded Theory: Theoretical Sensitivity* (1978).

## **Constant comparative analysis**

Constant comparative analysis is a fundamental technique of grounded theory. When using the constant comparative method of analysis, the data collection, coding and analysis occur simultaneously (Glaser & Strauss 1967). It is a method that allows the researcher to move back and forth within the data, to change focus and pursue new leads as they are revealed in the ongoing data analysis (Glaser & Strauss 1967). Glaser and Strauss (1967, p. 105) identify the four stages of the constant comparative method: '(1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimiting the theory, and (4) writing the theory.' Although the following diagram and summaries of this methodology may appear to be linear, the process is more

complex. This is because each stage of the process is continually revisited in any sequence throughout the course of the research. This method of generating theory is an evolving process and each of the stages are an integral part in the development of the grounded theory. Figure 3.2 shows a schematic representation of the four stages of the constant comparative method of analysis used in grounded theory.



**Figure 3.2: A schematic representation of the four stages of the constant comparative method of analysis**

Constant comparative analysis continues for the duration of the research. It begins with the coding of incidents that in turn lead to the emergence of categories and their properties, and finishes with the theoretical codes that connect the categories with each other and the core category or BSP. This means that all the data collected over the course of the research has been compared and analysed and that the theory that emerges is a true reflection of not only the data that has been collected but also of the participants involved in the study (Glaser 1992; 1978).

### **Substantive coding**

Substantive coding consists of two distinct stages:

**Open coding** is the first stage of constant comparative analysis. Open coding begins with raw data obtained from, for example, fieldwork observation or interviews, which have been transcribed in a verbatim fashion. The researcher

begins to code each segment of the data, examining it closely and comparing each portion of the data for similarities and differences (Glaser 1992; Glaser & Strauss 1967).

In this phase the data is coded in as many ways as possible (Glaser 1978). Examining the data word-by-word, line-by-line or even larger sections such as paragraphs or pages can achieve this. The researcher looks for emerging patterns, beginning with no preconceived conceptual thoughts or ideas. As explained the focus of grounded theory is that the research is grounded in the data. The researcher therefore is only interested in information that is obtained inductively from the data itself (Glaser 1992; Glaser & Strauss 1967).

During open coding many codes may emerge and as the process continues these codes are grouped together to form subcategories and categories (Glaser 1992). A category is a set of codes or concepts that are similar and are therefore by definition grouped together. It is at this stage of analysis that there may be some indication or evidence of a core category. A core category is the main category that explains the variations in the data and therefore the behaviour or actions of the participants in the research.

**Selective coding** is the second phase of analysis. In this stage the focus is usually on a limited number of categories that best represent the major aspects of the data. Selective coding is similar to open coding as data continues to be constantly compared and the researcher continues to look for similarities, categories and properties of categories. As in open coding, the researcher continues the search for a core category. Once the core category has been discovered it becomes the guide to ongoing data collection and theoretical sampling (Glaser 1978).

Selective coding is more analytical and uses conceptual and theoretical codes that become the foundations of the developing theory (Glaser 1978). Unlike open coding, which uses substantive codes (i.e. are in the participants' own words), selective coding is more analytical and abstract leading to conceptual names for categories. At each level of analysis there is more integration and a refining of the abstract concepts covering the variations in behavioural patterns of the research participants (Glaser 1978).

The search for a core category begins from the outset of data analysis. As codes and then categories emerge and are compared, the researcher is looking for the

core category that explains the main concern or problem for the participants. Glaser (1978, pp. 95-96) identifies the main criteria for core category selection:

- The core category should be central to as many other categories as possible. It should account for most of the variation in the participants' behaviour.
- The core category is frequently seen in the data. It is a recurring theme. It must also become more relevant to the other categories as the research progresses.
- The core category takes more time to saturate or expand than the other categories. Saturation occurs when the data yields no new information for a category.
- The core category has meaningful links to the other categories and these links can be quickly and easily identified.
- The core category in a substantive theory must also have relevance in a formal theory. Given that each substantive theory can be used in larger and more diverse formal theory applications, it is essential that the core category can be utilised to explain behaviour outside the parameters of the substantive area of research.
- The core category must have the ability to explain behaviour for the duration of the research analysis. Therefore it must be the central theme and offer a continuous explanation of participants' behaviour from the beginning to completion of the research. If the category fails to yield an ongoing explanation of the participants' behaviour, it is not a core category and a search for an alternative core category should begin.
- The core category must easily account for variations that occur as the relationships between the core category and other categories develop and expand. Therefore a core category is open to easy modification if required.
- A core category should also be a part of the problem itself. Therefore the core category should, in part, explain itself and its own variations.



- On occasions a core category may also be classified as a basic social process (BSP) which is explained below.

In comparison, Hutchinson (1986) succinctly states that there are only three essential characteristics of a core category. It must occur frequently, connect codes and categories together and explain the major variations in the data. She goes on to say that the:

... variable [the core category] becomes the basis for the generation of the theory. The categories, properties, phases, and dimensions of the theory are inextricably related to the core variable. The integration and density of the theory are dependent on the discovery of a significant core variable (Hutchinson 1986, p. 118).

Basic social processes (BSP), which are a type of core variable, are fundamental behavioural patterns that research participants exhibit over time (Glaser 1978). For a BSP to exist it must have two or more clear emergent stages or phases in its development. This is in contrast to a core category that has no procedural stages but is a stand-alone category. Stern (1980), for example, identified integrative discipline as the BSP in her study. She looked at how stepfamilies become a cohesive or integrated unit and the problems that hindered the process of integration. Integrative discipline was the BSP that explained the variations in the research data and because it had more than one clear emergent stage it was referred to as a BSP, rather than a single stage core category (Glaser & Strauss 1965).

A core category need not be a BSP, however a BSP is always a core category. There are two BSPs identified in grounded theory: firstly, a basic social psychological process (BSPP); and secondly, a basic social structural process (BSSP) (Glaser 1978).

Glaser also uses a term for denoting a BSP in formal theory called 'gerunding'. *The Websters New World Dictionary* (1974, p. 587) defines gerund as '...a verb noun ending in – ing, that has all the uses of the noun but retains certain characteristics of the verb, such as the ability to take an object or an adverbial modifier (Ex.: playing in "Playing golf is his only exercise")'. Glaser (1978, p. 97) says the following examples '... cultivation, defaulting, centering, highlighting or becoming, give the feeling of process, change and movement over time.' He warns that researchers need to be mindful of adding gerunds to core categories and treating them like a process as their use may cause over generalisation if a

theory has not been sufficiently developed. Gerunds are not usually a feature of substantive theory (Glaser 1978).

### **Theoretical coding**

This is the phase of coding in which the properties, connections or links between the categories and the core category emerge from the data (Glaser & Strauss 1967). It is also the stage where descriptive links between the categories are changed to more theoretical links (Chenitz & Swanson 1986; Glaser 1978). Glaser (1992) states that the theoretical codes are the conceptual connectors linking the categories to each other and the core category. It is these theoretical connectors that enable and guide the process of theory generation, development and integration (Chenitz & Swanson 1986; Glaser 1978).

There are a number of ways in which theoretical links or connectors can be established and represented. These include diagrams or models that represent the relationships between the categories and the core category. Alternatively the researcher may use one or more of the theoretical codes described by Glaser (1978). There are eighteen theoretical codes that Glaser (1978) refers to as coding families: the Six Cs, the Process Family, the Degree Family, the Dimension Family, Type Family, the Strategy Family, Interactive Family, Identity-self Family, Cutting Point Family, Means-goal Family, Cultural Family, Consensus Family, the Mainline Family, Theoretical Family, Ordering or Elaboration Family, Unit Family, Reading Family and the Models Family. These coding families are not mutually exclusive. The researcher may also find that as the analysis evolves one coding family may trigger the use of another coding family (Glaser 1978).

The theoretical codes known as the Six Cs is the family that Glaser (1978) recommends beginning grounded theorists use because most studies fit into a causal, consequence or a condition model. The Six Cs family, like the other coding families, is used to assist the researcher to identify the theoretical connectors between the various categories and the core category. To do this a series of questions are asked when analysing the data. Chenitz and Swanson (1986, p. 126) and Glaser and Strauss (1967, p. 74) give examples of the questions that should be asked of each category:

- Is this category a condition of some other category?
- Is it a cause, context or a contingency of another category?

- Does this category co-vary with other categories?
- Is this category a strategy?

During theoretical coding the researcher may find that there are unanswered questions that need to be explored. In order to address this more data is collected in the specific area of deficit, facilitating the saturation of the properties, categories or the core category enabling theory development to continue. This is achieved by a technique referred to as theoretical sampling (Glaser 1978).

### **Theoretical sampling**

Theoretical sampling is where only individuals, situations or literature that can add to the current categories, properties or links are sought out. Therefore only relevant data that will advance the theory is collected. Following open coding which identifies preliminary conceptual codes and categories there may still be theoretical questions that require answering. It is these questions that guide the researcher's future data collection as their existence demonstrates deficits in the theory development and hence a need to collect additional data to further advance a property, connection, category or core category to the point of saturation. It is at this stage of the research that the process of ongoing data collection is controlled by the emerging theory. Therefore only data that is relevant and will add density to the emergent theory is sought. This process is referred to as theoretical sampling (Glaser 1978).

### **Category saturation**

Category saturation occurs when theoretical sampling does not add any new information to the categories in the study. Saturation is also achieved if there is no new information available to the researcher to add to their understanding of the properties, connections or links between the categories and their relationship with the core category or BSP (Glaser 2002; Glaser & Strauss 1967). However, some researchers may decide to confirm findings with another group. This can lead to the discovery of a new perspective or information not found in the original area of study. If this occurs the researcher is left with the dilemma of pursuing the new lead or dismissing it as a negative case. The researcher is the only person in a position to make such a decision (Schreiber & Stern 2001; Glaser & Strauss 1967) and as the negative cases that emerged from the data in this study were not thought to be significant enough to change the theory, this option was not adopted. Therefore saturation is the point at which the researcher is satisfied

that no new information is available to further explain categories, properties or the links between categories and the core category or BSP (Glaser 2002; Byrne 2001).

## **Memoing**

The use of memos is also fundamental to grounded theory. Theoretical memos are the building blocks that enable theory generation and are also a reflective process enabling the researcher to analyse and make meaning of the data and the time they have spent with participants (Mills, Bonner & Francis 2006). So crucial is theoretical memoing to grounded theory methodology that if the researcher neglects to use memos or decides that they are not important in their theory development, they are deemed not to be employing grounded theory (Glaser 1978). Memos enable the researcher to document their ideas, thoughts, hunches, questions, emerging hypotheses and analytical schemata (Glaser 1992; 1978). This in turn enables the researcher to keep track of the emerging theory. Memos are ideational but because the ideas are sparked by the research data they are also grounded. They are a mechanism used for theorising ideas about codes, categories and the core category or BSP and their relationships, which are generated by the researcher during the life span of the research (Glaser 1978). It is these memos that are written during every phase of the research that are sorted and used in an analytical process to write the final substantive theory and subsequent report or thesis (Glaser 1978).

There are four basic goals in memoing:

- **To theoretically develop ideas:** Memos are used to develop theoretical ideas that are grounded in the research data. A memo can be as simple or as complex as the researcher desires. It can be a sentence, a paragraph, a page or a diagram. However, one of its main functions is to connect the research data with the final theory by raising the analysis of the codes to a conceptual level (Glaser 1978). It is this ongoing process, which draws out the theoretical properties of the data, codes, and categories that leads to category saturation and ultimately to theory development (Glaser 1978).
- **To develop ideas freely:** The second goal of memoing is to develop ideas freely. This means that there should be no constraints placed on the researcher. There are no grammatical rules when memoing - ideas can be typed, written or drawn (Glaser 1978). The sole aim is to

enable the researcher to document their ideas as they emerge. Also, memos are written for the researcher only and are not subject to scrutiny by others (Glaser 1978). They are the researcher's personal ideas to be used in theory development and to assist with their final report or thesis 'write-up'.

- **To develop a memo fund:** It is important to develop a memo fund as it provides, once sorted, the material required to write up the final study report or thesis. Theoretical memos are written over the course of the entire research project and therefore hold valuable information about the categories and the emerging theory. The memo fund is also the source of ongoing information for presentations and research articles associated with the study. It will also contain ideas for future research (Glaser 1978).
- **To provide memos that are highly sortable:** The final goal of memoing is crucial as the ideas and emergent theory must be quickly and easily accessible to the researcher as they move through each segment of theory development and reporting. In order to facilitate accurate and efficient sortability, each memo should have a title stating which code, category or property it is referring to. If there are other codes or categories referred to on the memo these should be highlighted and cross-referenced so that they too can be included in the appropriate category or categories (Glaser 1978). Furthermore, if there are two categories discussed on one memo, the relationship between the two needs to be highlighted to ensure that this information is sorted correctly during the theoretical sorting phase of the research (Glaser 1978).

It is important that memos are not written on data documents or field notes as this renders the memos much less sortable and makes such a process extremely cumbersome. At least two copies of the memos should be available - one copy which can be cut up at the time of theoretical sorting and another master copy which contains all memos relating to the study (Glaser 1978).

### **Theoretical sorting**

Theoretical sorting is the key component of theory generation and it begins toward the end of coding when categories are nearing saturation. The purpose of theoretical sorting is to sort the memos that the researcher has written over the

course of the research in order to identify the emerging theory. It is a crucial step in the grounded theory process and provides the essential preparation for the theory write up (Glaser 1992).

It is the theoretical sorting that enables a generalised, integrated, complex and dense theory outline, as it highlights the connections between the categories, core category or BSP and their properties. This process provides the organisation for the first draft of the thesis and a sense of theory completeness (Glaser 1992). These memos are notes, pictures, diagrams, comments, hunches and hypotheses written or drawn from the beginning of data collection and coding, until the completion of the final write up of the thesis. Memos are important to theory development as they catch the researcher's thoughts at the time of analysis and are an ongoing accurate record of the theory development and the research processes (Glaser 1992).

This sorting process may also lead to the discovery of the core variable or BSP if it has not already been discovered. The major focus of the sorting process is to put back together the fractured data collected during the research in an effort to provide a whole picture of the substantive area under scrutiny (Glaser 2002).

## **Common problems when using grounded theory**

Becker (1993) highlights the following pitfalls for grounded theorists believing that many researchers claim to have produced grounded theory research but have in fact only delivered elaborate descriptive studies. She identifies the common problems associated with descriptive studies that claim to be grounded theory. These include:

- a failure to identify the problematic situation in the research area.
- a failure to use theoretical sampling to make sure the theory produced is adequate.
- a failure to use the correct theoretical lens for the proposed research question.
- a failure to concurrently engage in both data collection and analysis.
- a failure to identify the correct core variable due to reliance on computer programs, which manage data with the identification of the

core variable being based solely on the frequency of its occurrence in the program.

## **Grounded theory and this study**

Grounded theory as developed by Glaser and Strauss (1967) is the methodology chosen for this study about the issues and challenges that impact on transplant coordinators and their practice. The reason for this is that there is limited research regarding transplant coordinators and their role in the literature and it is therefore a relatively new area of inquiry. Grounded theory is particularly suited to research in areas which have had limited or no investigation. Stern (1980, p. 20) states that '... the strongest case for the use of grounded theory is in investigations of relatively uncharted waters, or to gain a fresh perspective in a familiar situation.' She also believes that it is helpful in studying complex areas of human behaviour where salient variables have not been identified. Appendix 2 shows an overview of the study as it relates to grounded theory methodology.

## **Combining qualitative and quantitative methods**

This research is primarily an interpretive study with an empirical component, which amalgamates both qualitative and quantitative data and data collection methods. Traditionally the methods of choice for empirical research focus on the formal testing of hypotheses in experimentation. The aim of this is to control extraneous variables and then manipulate the external environment in order to observe the effects on the research subjects (Polgar & Thomas 1999). This seeks to explain behaviour through observable, objective and quantifiable methods (Avis 2003; Polgar & Thomas 1999).

In comparison, interpretive research includes subjective perspectives of the research participants and seeks to highlight and appreciate the views, feelings, opinions and beliefs of those in the study. In interpretive studies the researcher attempts to see the world through the participant's frame of reference, seeking to study them as a whole, embracing their reality as they themselves view and describe it (de Laine 1997; Polit & Hungler 1997).

The use of qualitative and quantitative data in a single study has been the subject of much debate (Freeman, Demarrais, Preissle, Roulston & St. Pierre 2007; Bryman 2006; Greene & Caracelli 1997; Sandelowski 1995). Qualitative and quantitative methods in combination are known to add scope to research. Advocates for mixed method techniques argue that the diversity and complexity

of the human experience mandates that more complex research designs be applied to capture the essence of those in the study (Sandelowski 2000). Despite this interest, there is limited direction on how to successfully accomplish such an undertaking. There are also scholars who are not in agreement with the concept of mixed methods. Rossman and Wilson (1985) describe researchers as falling into one of three distinct groups, these being purist, situationalist or pragmatist.

The purists' focus is on the paradigm and their belief that quantitative and qualitative approaches are different with each having their own epistemological and ontological assumptions about research and society (Beattie 2002; Carey 1993). *Purists*

The situationalists' focus is on research methods and they believe that both approaches are of equal value. Although each approach is seen as important and both may be used in a single research study, situationalists believe that particular methods are more appropriate for some research applications (Carey 1993). *Situationalists*

The pragmatists' focus is on the integration of research methods in a single research project (Patton 2002). Lederman (1991) sums up the benefits of using and integrating qualitative and quantitative methods: *Pragmatists*

Quantitative and qualitative methods of research are not necessarily diametrically opposed. ... The critical issue is to value different nursing research methods and permit different research methods to evolve so that nursing can benefit from the strengths of different methods, paradigms, and outcomes in the advancement of nursing knowledge and the evolution of our science (Lederman 1991, p. 43).

Sandelowski (2000) asserts that mixed method studies using a combination of qualitative and quantitative data, are operationalised at the methods stage of the research, which is at the sampling, data collection and analysis level. Articulating that to mix paradigms is to espouse two entirely different viewpoints of the world that are separate and quite different (Sandelowski 2000). For example it is not possible to reconcile a positivist view of reality, which is singular and objective with a constructivist view that explores multiple, experientially and socially based realities (Sandelowski 2000). To do so would be like mixing oil and water!

Sandelowski (2000) argues that it is not a mixing of paradigms that occurs but rather paradigms are reflected in the techniques the researcher applies and how they choose to combine them. This is evident in the current study, which utilises



grounded theory methodology within a constructivism paradigm. The use of both qualitative and quantitative data does not alter the paradigm or indeed the methodology however, the mixed methods do add to the overall scope and depth of the research inquiry. The synergistic effect of combining qualitative data from focus group interviews, Delphi survey questionnaires and the literature with quantitative data obtained using a Likert scale in the Delphi surveys adds a dimension to the study, which would not be possible with a single method technique. Greene, Caracelli and Graham (1989, p. 259) believe there are three reasons for combining methods:

- **Triangulation** – to use multiple methods in order to corroborate or obtain convergent data validation.
- **Complementarity** – to elaborate, explain or clarify the results of data analysis.
- **Development** – to guide or inform additional sampling, data collection or analysis techniques.

This study uses triangulation, which is explained in the following chapter. There are also elements of complementarity and development reasoning within the research, as will become evident. The final issue to consider in interpretive studies is that of rigour and this is discussed below.

## **Determining rigour in interpretive research**

The issue of rigour in interpretive research and the criteria that should be used have been addressed by many scholars in the literature (Rolfe 2006; Schneider 2003; Davies & Dodds 2002; Morse, Barrett, Mayan, Olsen & Spiers 2002; Maggs-Rapport 2001; Emden 1999; Morgan 1998). There has been much debate surrounding this issue and numerous opinions and arguments have been put forward as to how best to address this perennial problem. Reliability, validity, objectivity and generalisability in empirical research are a less vexing issue, as there are distinct mechanisms and processes by which these requirements can be achieved. Progression in interpretive studies is less transparent and decisive with many confusing terms and processes used to address rigour.

In relation to scientific inquiry Polit and Hungler (1997, p. 467) defined reliability as 'The degree of consistency or dependability with which an instrument measures the attribute it is designed to measure.' Polit and Hungler (1997, p.

471) also define validity as 'The degree to which an instrument measures what it is intended to measure.' Other terms that are associated with empirical research include objectivity and generalisability. Polit and Hungler (1997, p. 462) describe objectivity as the extent to which independent researchers doing the same research would come to the same or similar conclusions. They state that objectivity is highly desirable within the positivist paradigm. Generalisability refers to whether or not the findings in relation to a sample group can also be used to make inferences about the whole population (Polit & Hungler 1997, p. 458).

There have been various criteria suggested by scholars for determining rigour in interpretive research with most arguing that the traditional descriptors referring to validity, reliability, objectivity and generalisability are inadequate when using an interpretive paradigm (Davies & Dodds 2002; Hutchinson 2001; Whittemore, Chase & Mandle 2001; Koch & Harrington 1998). The concepts of traditional indicators of rigour are not rejected but it is believed that the descriptive terms or linguistic representations used should reflect the qualitative nature of the research. Examples of alternative terms used by Guba and Lincoln (1989) are credibility, transferability, dependability and confirmability. Beck (1993) uses the terms credibility, fittingness and auditability whilst Koch (2006) and Wolf (2003) suggest a 'decision or audit trail' to establish trustworthiness and rigour. This process involves the concepts credibility, dependability and transferability.

The greatest difficulty when using qualitative data is that there is no single way of assessing rigour in these studies. It is incumbent on the researcher to find the most appropriate means by which to assess rigour in their own interpretive research, ensuring that these measures are a true reflection of the methodological assumptions being used in their particular study (Roberts & Taylor 1998). Koch (1996) reflects this:

The responsibility lies with the writer to show the way in which the study attempts to address the issue of rigour. It is for the reader to decide if the study is believable (Koch 1996, p. 178).

As this research is a grounded theory study, terms such as validity, reliability, objectivity and generalisability are inappropriate indicators of rigour. The purpose of grounded theory is not to validate findings but to develop a theory, which identifies the major concerns of the participants in the research (Glaser & Strauss 1967). With this in mind **credibility**, transferability or **fittingness**, dependability or **auditability** and **confirmability** as described by Guba and Lincoln (1989),

Sandelowski (1986) and Schneider (2003) have been adopted as indicators of rigour in this study. A brief and simplified overview of these terms, how they relate to research using qualitative data and how the criteria was used in this study, is discussed below.

Guba and Lincoln (1989), Sandelowski (1986) and Schneider (2003) suggest using credibility as an alternative to internal validity. In empirical research, which utilises quantitative data, internal validity relates to the truth-value of an instrument and how well it measures what it is designed to measure. In contrast, research that uses qualitative data is said to be credible if the researcher has been faithful to the data and participants in the study. In order to achieve this the researcher must identify and accurately describe the research participants, data and the setting within which the study took place (Crookes & Davies 1998). Credibility is further enhanced if the researcher is able to clearly articulate the impact they may have had on the participants and/or the research (Sandelowski 1986). The true test of credibility is demonstrated when the participants read the research and recognise it as their own experience or alternatively others recognise the experience as being true and authentic upon reading the thesis (Sandelowski 2000; 1986).

The tenets of credibility were achieved in this study by ensuring the parameters of the research were clearly defined and the participants in the study were carefully described, including a background section on transplant coordinators. Other mechanisms used in the study to ensure accuracy were the audiotaping of the focus group interviews, which were then transcribed in a verbatim fashion and checked several times for accuracy. Credibility was also enhanced with the assistance from health professionals and academics that were used to pilot the focus group interview schedules and Delphi surveys. Finally, memos documenting the researcher's thoughts, ideas, potential and actual concerns were also measures undertaken to ensure the accuracy and hence credibility of the data collected throughout the study.

Guba and Lincoln (1989) suggest substituting transferability for external validity and Sandelowski (1986) recommends using the term fittingness. In empirical research external validity addresses the generalisability of research findings from the study cohort to the study population. Can the findings from the research be used to make inferences about the study population as a whole? Much of the criteria relating to external validity in traditional scientific research relates to the

sampling techniques utilised in the study and whether or not the subjects in the cohort are a representative sample (Sandelowski 1986).

The samples generated in interpretive studies, in contrast, are often small and do not conform to the stringent criteria of empirical research. How then can external validity be addressed by the terms transferability or fittingness? Sandelowski (1986) argues that if the experiences of the study participants in interpretive paradigms are well documented, then the findings represent a small component of the greater population. It is the researcher's belief that the current study will fulfil the criteria for fittingness if participants and/or other transplant coordinators who read the thesis believe that the described issues and challenges are experiences familiar, or potentially familiar to them. This thesis will then be considered to have some representative component in relation to others in the population.

Auditability or dependability are the parallel terms used in interpretive research for reliability, which is the term used in the positivist paradigm. Reliability refers to the ability to replicate the findings of a study. In other words could another researcher using the same research design and methods deliver the same or similar findings (Polgar & Thomas 1999)? Are the results reproducible?

In contrast researchers who use qualitative data are not aiming to have their findings replicated. They are striving to achieve an authentic representation of their participants' experiences as they themselves view and describe it. This sentiment is aptly described by Janesick (2000):

Somehow we have lost the human and passionate element of research. Becoming immersed in a study requires passion: passion for people, passion for communication, and passion for understanding people. This is the contribution of qualitative research, and it can only enhance educational and human services practice. In the other paradigm, people are taken out of the formula and, worse are often lumped together in some undefinable aggregate as if they were not individual persons. In the qualitative arena the individual is not only inserted into the study, the individual is the backbone of the study (Janesick 2000, p. 394).

In order to achieve the understanding described by Janesick (2000) the researcher attempts to capture the uniqueness of the human experience, entire with complexities and contradictions. There is no want for definitive answers but rather for a greater understanding of the participants' world and how they interact within it. Therefore dependability or auditability are more accurate terms when discussing research that uses qualitative data. If the researcher has articulated

decisions or documented an audit trail, throughout the course of the research, another should be able to follow the guidelines and reach similar conclusions.

Auditability was addressed in the current study using the following processes. The study design and methods of data collection and analysis were clearly documented. The researcher also used an audit trail to enhance the auditability of the study, which is discussed below.

With respect to the cannons of empirical research objectivity refers to a study being free from bias (Sandelowski 1986). Sandelowski (1986) and Guba and Lincoln (1989) suggest that researchers using qualitative data utilise the parallel term confirmability. Patton (1997) states that the researcher should also aim for fairness, completeness and balance. In an attempt to address this aspect of the criteria for rigour, the researcher articulated assumptions regarding the research area at the beginning of the study and also declared herself as a transplant coordinator - an insider in the field of inquiry. She also regularly met with her supervisor to discuss research and decision-making processes.

The other indicator of rigour, which is suggested as useful in research using qualitative data, is an audit or decision trail (Koch 2006; Polit & Hungler 1997). As described, an audit trail is a transparent, well-articulated and easily followed account of the decisions made by the researcher throughout the course of the study. Koch (2006) and Smith (1999) state these may include field journals, how access to the participants was obtained, a description of the setting and equipment, an exploration of one's experiences and decision-making processes. The audit trail used in this study is woven into the fabric of the thesis in the form of documented evidence highlighting how decisions were made throughout the research. This is further complemented by the use of memos, participant and literature examples, diagrams and supporting documents where appropriate.

## **Summary**

Grounded theory methodology has been chosen as the theoretical framework for this study as there is limited research on these health care professionals and the role they play in organ donation and transplantation. Grounded theory is appropriate for such areas of inquiry as it offers a systematic approach to data collection and analysis that will result in a theory that adequately reflects the central issues and challenges that impact on the participants and their practice.

The chapter began with an overview of research paradigms including the concepts encapsulated in a paradigm. These concepts are ontology, epistemology, theoretical perspectives, methodology and axiology. This was followed by consideration of symbolic interactionism and pragmatism - the two theoretical perspectives that influenced grounded theory methodology. An historical summary as well as ensuing modifications were then examined. Grounded theory offers a method for conducting and evaluating research - this aspect of the methodology was thoroughly discussed, as were associated common problems.

The chapter concluded with a discussion about the use of mixed methods. The final aspect addressed the issue of rigour when using qualitative data and observed how it could be achieved. This included the use of alternative evaluation criteria, which are more representative of the qualitative nature of the research. Also addressed was how the use of an audit or decision trail can add authenticity and trustworthiness. The following chapter examines the research methods employed in this study.