Chapter 5
Analysis of focus group data

Introduction

This chapter reports on the analysis of the data collected during the focus group interviews. The analysis was conducted in a systematic but non-linear fashion using the constant comparative technique of analysis as described in Chapter Three.

When using the constant comparative method of data analysis data collection, coding and analysis occur simultaneously (Glaser & Strauss 1967). Although the analysis and results chapters are written in what appears to be defined stages of a linear process, in reality this process was non-linear. During each phase of data analysis, new data, concepts, ideas and propositions were constantly compared with the previous data. Each step of the process added to the integrity, accuracy and authenticity of the work presented. Glaser and Strauss (1967, p. 5) state there are four stages involved in the constant comparative method of data analysis: '(1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimiting the theory, and (4) writing the theory.' This and the following chapters encompass these four stages.

In conjunction with the constant comparative method of data analysis and in keeping with grounded theory methods, memos were written throughout the research to assist with theory development. Thoughts, ideas and questions about the emerging concepts, codes, preliminary categories and categories were continuously documented and used to assist in data analysis and subsequent substantive theory development. An example is a memo that was written immediately following the recipient coordinator's focus group interview:

> I am surprised that there was not more discussion in relation to process issues during the focus group interview tonight. For example the length of time it takes to organise the transplantation process. Perhaps this indicates that there are other more pressing issues that personally effect coordinators, which need to be addressed before global concerns can be confronted.
>
> It is almost like Maslow's hierarchy of needs where people are unable to self-actualise until their basic needs for food and shelter are met. Until coordinators' needs for more staff, less on call and adequate debriefing

> avenues are addressed, the more global aspects of the role it seems cannot be explored.
>
> I get a sense that there is ambivalence for some coordinators in the role. On one hand the recipient coordinators love the job, enjoy the variety of people, the autonomy and the joy of seeing recipients go back to their lives. The recipient coordinators' believing what they do is important and unique work.
>
> On the other hand they are frustrated by medical staff, donor coordinators who are inflexible about theatre times, inexperienced staff, non-nurse coordinators, on call demands and excessive working hours and workloads. They appear to have a love/hate relationship with the job (Memo RFG 5.9.01).

The first focus group interview conducted involved the recipient coordinators and was followed two weeks later by the donor coordinator focus group interview. Each of these interviews was audio taped and using the tapes labelled number one, the interviews were transcribed in a verbatim fashion. The accuracy of the transcripts was cross-checked with the second and third audiotapes. They were then printed for the participants with different codes on the front cover of each, R1-R5 for the recipient coordinator group and D1-D5 for the donor coordinator group. This was to record who had returned transcripts in the event that reminder letters were required.

Each participant in the focus group received the transcript from the interview they participated in. For reasons of confidentiality the participant's first name, which was used during the focus group interviews, was replaced with a code in the transcript and they were notified of the code in a letter that accompanied their transcript. Participants were asked to review the transcript and provide any comments they wished and return it in the pre-paid envelope provided.

Six participants, two recipient coordinators and four donor coordinators made changes or added comments to their transcripts. Comments and/or corrections ranged from grammatical errors, with one participant commenting on how different the spoken word is compared to the written word, whilst others wrote lengthy comments elaborating on issues discussed in the focus group interviews. In two cases, issues not raised in the focus group interviews but considered important to the research were also discussed. Following the return of the transcripts, a letter was sent to every focus group participant thanking them for their input and support (Appendix 25).

The focus group interviews were conducted prior to the commencement of analysis of the interview data. This was to minimise the potential for the

researcher to lead the donor coordinator focus group participants to discuss issues that had been examined in the recipient coordinator interview. The recipient coordinator focus group interview data was analysed first, followed by the donor coordinator focus group interview data. During analysis of the second interview, the data was constantly compared with the first to highlight incidents, events and areas of interest. Both similarities and differences in data were noted during this process. Similar and dissimilar data are equally important to the research analysis. Similar data is grouped together to form codes, preliminary categories and categories and dissimilar data contributes to the emergence of the category properties and the links between categories (Glaser & Strauss 1967).

Recipient coordinator focus group - open coding

The five participants in the first focus group interview were recipient transplant coordinators employed in the area of transplantation. To facilitate the focus group interview process the participants were asked to discuss the following questions:

- What are the good things or issues that help you or enhance your practice?
- What are the negative things or issues that hinder you or detract from your practice?

Prior to analysis of the recipient coordinator focus group data the researcher comprehensively read the interview transcript and again listened to the audiotape. This enabled an overview of the information before beginning the analysis. This process was repeated for the donor coordinator focus group interview.

The initial stages of analysis began with 'set one', which was the raw verbatim transcript data that included the participants' first names. No examples of this set are included in the appendices for reasons of confidentiality as the participants' names had not been removed at this stage. During the next phase of data analysis, first names were substituted with a code to maintain the confidentiality of the participants, and each line of the text was numbered to assist in the analysis process. This set of data was labelled 'set two'. A detailed examination of the data followed where the content of the transcript was coded line-by-line, sentence-by-sentence or paragraph-by-paragraph in order to make sense of the

data and to facilitate the emergence of preliminary codes, codes and preliminary categories. Each area of interest was highlighted using a coloured pen. This was then labelled 'set three'.

In 'set four' the highlighted data was copied to a new document on the word processor with each concept, code, line, sentence, paragraph or page that had been selected, having an identifier attached to it. This highlighted which focus group the selected text had come from and on what page and line or lines it appeared. Therefore 'set four' contained only data that was to be grouped together to form the codes in the next set. Redundant data was discarded.

The 'set five' phase involved grouping together like words, concepts, sentences or paragraphs to form codes. An example of how the data was coded can be seen in Appendix 26 and examples of 'sets two – five' can be seen in Appendix 27. In this phase of analysis where codes were emerging, the actual words or terminology of the participants were used to describe the code. For example:

> ... the autonomy ... (RFG, p. 10, L. 4) and ... the autonomy in the job ... (RFG, p. 9, L. 26) were grouped together to form the preliminary code **Autonomy.**

Dissimilar data was not discarded as it was significant in the analysis and was used where similar and dissimilar data appeared as separate codes within a preliminary category or category. Later in the study this data was also used to identify properties of categories and links between categories and the core category/BSP (Glaser & Strauss 1967). Once the data was coded and compared manually the verbatim transcripts of the interviews were transferred to the QSR NUD*IST Vivo (NVivo) software package where the process of constant comparative analysis was rechecked and continued.

Forty-four codes were identified from the recipient coordinator focus group interview data. Each of these codes contained words, phrases or concepts with similar meaning. The codes are discussed below with one or more examples of the words, concepts or sentences that emerged in each code. It is acknowledged that there is significant overlap in many of the codes as much of what the recipient coordinators discussed was represented in more than one code.

Advocacy

All the recipient coordinators indicated that a significant element of the role is patient *advocacy.* In the case of paediatric patients this *advocacy* was also seen

as pertaining to recipients' families. There was considerable discussion about direct patient *advocacy*, as shown in the examples below in relation to advocating directly for patients' rights. This extended to *advocacy* for patients in the form of tailoring the job to meet the needs of recipients and potential recipients, accommodating patients and coordinating services to meet their requirements:

> ... I see it as my job to be the advocate for the parents to be letting the parents know what [is] going on. It's their child they have entrusted to us or to the team. Yes they've had a say in it, they've signed the consent form but you're there to support them (RFG, p. 65, L. 7-9; L. 13-15).
> ... you're the patients' advocate (RFG, p. 32, L. 10-11).

Autonomy

As with *advocacy* there was agreement amongst the recipient coordinators that *autonomy* is one of the most important and appealing aspects of the role, as is highlighted in the first example. In the second example the coordinator states that they are often required to make autonomous decisions because there is no one else available to assist them. However, another code that emerged from the data was *professional isolation*, which appeared, in part, to contradict the concept of *autonomy:*

> ... the autonomy in the job, that we've a reasonable amount of autonomy (RFG, p. 9, L. 26-27).

> ... you are autonomous you're the only one there, there is no one else to ask ... there is no one else there you can go through and you ask your consultant and wait all day for him to come out of the operating room and then he will say yes do that. I mean it's easier to ... get it all happening and then reverse it later if he [the doctor] doesn't want it (RFG, p. 18, L. 6-11).

Professional isolation

The codes *professional isolation* and *autonomy* appear to be linked and this is demonstrated in the second example below. What may be *autonomy* for one coordinator may be experienced as *professional isolation* for another. The first example highlights the belief that other professionals have limited understanding of the role and issues that coordinators face. The second underscores the dichotomy between *autonomy* and *professional isolation*:

> ... the professional isolation because ... I've been the only one ... in the hospital for quite a number of years ... you didn't have a sense that a lot of people had empathy with your issues (RFG, p. 29, L.. 18-22).

> ... your practice, autonomy of practice because you know ... your business and you know what the patients need and ... there isn't anyone else there (RFG, p. 18, L. 23-25).

Budget issues

There was significant discussion about the difficult and sensitive issue of overtime payment. However, there was also some sympathy expressed for those who negotiate for funding. Coordinators are aware that if there are no funds available it presents problems for directors with regard to remuneration for staff. There was also acknowledgement of the costs involved in the organ donation and transplantation process, particularly if mistakes are made as is demonstrated in the second example:

> ... it's OK to have it at that level but if you haven't got the dollars in [the] ... budget to pay you ... I'm very lucky that ... the consultant ... of my unit will sign my time card no matter how many hours of overtime are on it ... but if they haven't the money 'bickies' in the tin and administration won't give them anymore ... (RFG, p. 75, L. 16-17; L. 27-29; p. 76, L. 1-3).

> ... that is just one of the incidents that I can think of but there are many and that was a very big ... waste of money, I flew planes everywhere all over the place you know, it was just a nightmare (RFG, p. 18, L. 23-25).

Communication

Poor *communication* from medical staff was a concern for recipient coordinators as they indicated it directly impacted on the service they provide. One example of this was staff needing to reschedule appointments for patients and their families, causing unnecessary inconvenience for clients, when doctors forgot to communicate their leave arrangements:

> ... you feel that hell who do I turn to now, and the lack of communication ah you know you book kids for out patients on days that suit the parents or try and arrange all their appointments together ... and you do it and then he [the doctor] turns around and he says to you oh I'm going to have leave that week didn't I tell you? (RFG, p. 31, L. 23-26; p. 32, L. 4-5).

Compromise/flexibility

Discussion centred on the Australian donor coordinators and the perceived lack of *flexibility* that is sometimes evident during the organ donation and transplantation process. Recipient coordinators believe that some donor coordinators can dictate theatre times without considering the needs of the transplant units, who may have potential recipients several hours away from the hospital. The recipient coordinators are frustrated by this, as they need adequate time to transfer these potential recipients if they are to receive a transplant. However, the recipient coordinators said that if the donor is medically unstable, they understand and respect the need to proceed urgently with the organ

retrieval. What is being suggested is the desire for a greater level of understanding of the difficulties recipient coordinators face in the organ donation and transplantation process, and for donor coordinators to be more flexible and accommodating. These issues, however, do not appear to be problematic for the New Zealand recipient coordinators:

> ... I think some degree of flexibility has to come in because there are constraints in this country on aircraft ... (RFG, p. 48, L. 11-13).

> But there are two sides to this story and ... we've got to work to compromise sometimes ... I want them to hear ME and to hear me say OK I've got a recipient four hours away ... And just be a LITTLE more accommodating (RFG, p. 43, L. 24-27; p. 44, L. 1).

Correct information

The need for *correct information* emerged as a significant issue in the focus group discussion. All participants stated that *correct information* is vital for efficient and positive transplant outcomes. The code is also linked to the code that discusses the educational backgrounds of transplant coordinators *nurse - non-nurse.* It was felt that donor coordinators without a nursing background are often 'transcribers', who document information but have little understanding of what is meant by it, or the consequences of errors in transcription. Recipient coordinators indicated that sometimes these donor coordinators do not give the *correct information* or all the appropriate information due to a lack of knowledge and understanding:

> ... I'm finding that of late ... I've got somebody giving me information and they actually ... are purely transcribers they don't actually know the significance of, if a patient is on a particular drug and is on a particular dose and don't actually ... can't interpret ... that information (RFG. p. 54, L. 8-12; L.16).

Credibility

The focus group participants indicated that professional *credibility* is important. They state that *credibility* is gained over time, implying you have to earn it:

> ... it's professional credibility and I think it reflects on how individuals perform their duties and ... that is something that ... is developed [pause] that credibility, when I say developed, I think it's ... gained (RFG, p. 17, L. 7-9; L. 13-15).

Debriefing

The area of *debriefing* is complex and discussion revolved around informal and formal opportunities to talk about concerns relating to the work environment and

the coordinators' practice. There was some overlap with other codes such as *professional isolation* and *support people*. The coordinators spoke about others not fully understanding their role and issues. For some, *professional isolation*, particularly in the case of sole practitioners, contributed to the fact that their avenues for informal *debriefing* were limited. Forms of *debriefing* and stress release utilised by coordinators in the group included family support, dealing with problems on their own and having a few drinks after work. One coordinator also suggested exercise and retail therapy as a good way of relaxing and dealing with the stresses of the job. Others spoke of the support they receive from colleagues and how important it is to *debrief* with the right person, as the example below demonstrates. Another coordinator spoke of the need for formal *debriefing* but quickly pointed out, that support came from outside the hospital as she did not trust anyone within the hospital network:

> I debrief to ... the other coordinator ... who I work with because she understands ... the difficulties, the draining patients who ... emotionally, physically and psychologically completely drain you of everything you have (RFG, p. 37, L. 18-22).

Difficulties with doctors

Another issue that coordinators discussed was the difficulty experienced with surgeons who are not technically proficient in organ retrieval and transplantation. This, they said can and does lead to negative transplantation outcomes. This was not an issue for all the coordinators and it appears that it has been a recent issue as indicated below:

> I know that they ... work long hours and ... [they're] under a lot of stress and strain and I forgive them most of the time, except for occasionally [laughter] ... the lack of ... experienced [sigh] surgical staff ... we don't have the ... expertise that we need ... in the recipient theatres ... in the ... donor theatres. I've seen that as a problem over the last year or so (RFG, p. 28, L.6-14; L. 18-19).

Education

The training, *education* and qualifications of transplant coordinators were discussed. Several coordinators spoke of the length of time they trained and the study commitment they had made to work in the field. The type of *education* and qualifications they believe transplant coordinators should possess was also discussed. This code is strongly linked with the *nurse - non-nurse* and *experience* codes. There is strong agreement from the recipient coordinator focus group participants to support the idea that all transplant coordinators should have a nursing background:

> ... I've trained long and hard ... in this field and I think that I've got something to contribute to these patients (RFG, p. 78, L. 26-28).

> ... we were unsuccessful at finding someone ... with the right qualifications ... we took someone on ... who ... didn't have the ... right qualifications but ... was keen and hopefully that person will turn out alright (RFG, p. 72, L. 15-19).

Nurse – non-nurse

The issue of whether transplant coordinators should be registered nurses provoked significant dialogue. It was agreed that transplant coordinators should be registered nurses, as was the case with all the participants in the recipient focus group interview who were registered nurses themselves. The reasons they gave were that *non-nurses* generally do not understand the information they are collecting and dispensing to transplant units. There is an associated risk of negative outcomes and unsuitable organs are sometimes offered to transplant units. The other concern is that *non-nurses* make standardisation of the role difficult if not impossible:

> Because you know they [non-nurses] can't interpret ECGs ... they don't know what is relevant I mean I've had incidences where I've, we've travelled hundreds of miles and to get there and find that there is a CT Scan been done of a CT chest and that the patient had bilateral emphysema, emphysemetic changes and they offer me lungs ... (RFG, p. 55, L. 18-23).

> ... the person who's delivering it [the information] should have an understanding (RFG, p. 58, L. 22-23).

Experience

Participants discussed the *experience* they had gained in the role. One coordinator talked about evolving in the role and others discussed how personal *experience* and quite a few years of work enabled them to know their area, and in turn pass on their *knowledge* and *experience* to others:

> I would say ... a lot of personal experience, quite a few years ... and also ... when you've worked with these people for a long time and when new ... doctors come to ... the unit you train them ... and you take them on the donor runs and you tell them how to do it and you tell 'em what time to be there ... (RFG, p. 19, L. 16-21).

Frustration

One source of *frustration* for the recipient coordinators was poor *communication* from medical staff, which they believed disrupted patient and family care. This code overlaps with the *communication* and *advocacy* codes. Other causes of *frustration* were the lack of negotiation from donor coordinators especially relating

to the issue of theatre times for organ retrieval, ungrateful transplant recipients and the constant fight to have smaller transplant units recognised for the essential work they perform and service they provide:

> And you're the parents' advocate ... we do transplantation for these kids ... to lead normal lives. We don't do it so they spend their life in the blasted hospital, or on the road travelling. There are other kids in these families there are other demands. You know ... it's very frustrating (RFG, p. 32, L. 15-18; L. 24-26).

Going back to their life

Recipients *going back to their lives* seemed to be very important to the recipient coordinators and this was reflected in the examples below:

> ... the most positive thing ... [is] seeing them walk out that door and knowing that they are off to start their life again (RFG, p. 9, L. 1-2; L. 7-8).

> Walking out the door and saying goodbye going back to their life ... (RFG, p. 8, L. 31; p. 9, L. 1).

Job satisfaction

This was a code that overlapped with many others from the recipient coordinator focus group interview. However, there were several examples where it was appropriate for data to be placed into the code *job satisfaction*, as they did not fit adequately into the other codes:

> ... I think we're really lucky in ... what we do because um there's a lot of satisfaction on the job (RFG, p. 21, L. 28-29).

> ... the more you put in the more you get out of it (RFG, p. 22, L. 13).

Knowledge

This code is linked to the codes *education* and *experience*. The coordinators discussed the concept of *knowledge* in terms of knowing their business and knowing the patients' needs. There was acknowledgement of the amount of study most of them had done in the area and that most had worked with transplant patients for a long time:

> ... they [doctors] come to you and ask you, the nurses come to you and ask you, so I don't know it just gets that you just have ... this huge body of information that's just there all the time you know and it's increasing all the time as well (RFG, p. 19, L. 22-26).

Learning others' role

Recipient coordinators generally agreed that participation in the organ retrieval process would assist them in their understanding of the donor coordinator's role. They also believe that donor coordinators would benefit from participating in the transplantation process to increase their understanding of the recipient coordinator's role. In New Zealand this initiative has already been addressed with all recipient coordinators having participated in the organ donation process:

> ... from my point of view I think it would be important for recipient coordinators to go on a donor run ... to ... do a donor run with ... the donor coordinators to see what they go through and visa versa ...FG, p. 46, L. 1-3; L. 7-8).

Making changes

The coordinators highlighted the difficulties of *making changes* in their working environment and to their role. Their desire for change is multifaceted. There is the issue of excessive amounts of on call work, which some recipient coordinators are required to undertake. Acknowledged too is the issue of working under different awards and the employment of coordinators from various professional backgrounds, which they believe further complicates their quest for *making changes*. Others believe that with the current greater pool of coordinators there is more opportunity to *make change*. In the example below one participant discusses how her philosophy regarding work conditions has changed over time and how coordinators in the past have contributed to unsatisfactory work practices:

> ... I ... now take issue with the expectation of our roles and sometimes I think as coordinators we have accommodated and promoted that expectation and the expectation to be up all day and all night and ... the next day. You know we've all done it. I ... have changed my whole philosophy on that and I think as a profession we should be more active in making sure that that shouldn't have to happen. I think ... we've been around long enough now to say it shouldn't be required and we ought to have the resources ... (RFG, p. 66, L. 1-5; L. 9-13).

Negative outcomes

As with other emerging codes, there was significant overlap between the code *negative outcomes* and a number of the others discussed here. The major causes of *negative outcomes* as perceived by the recipient coordinators include: inexperienced surgeons, inexperienced donor and recipient coordinators, conflicting personalities, poor transplant outcomes, aggressive potential recipients, ungrateful recipients, 'third hand' information, marginal organs,

inflexible theatre times, donor coordinators who are purely transcribers and losing organs for any reason. All of the above have the potential to lead to *negative outcomes* for donor families, potential recipients, recipients and health professionals involved in the organ donation and transplantation process:

> ... it turns to a negative outcome you know if you've got somebody, if you've taking a surgeon who's not technically um up to standard you can ... end up having negative outcomes. Which is not good for the whole process (RFG, p. 28, L. 23-26; L. 30).

Occupational health and safety

The main issues concerning *occupational health and safety* were the long hours that coordinators work and the on call load many have to cope with. This code was linked to the codes *on call demands* and *workload.* The examples below indicate *occupational health and safety* pressures recipient coordinators contend with:

> Up all day and all night and you know having to come the next day and a lot of us have done that on a number of occasion ... there are safety issues in that you know ... (RFG, p. 67, L. 9-11; L. 15).

> ... you're available all the time ... (RFG, p. 83, L. 1-2).

> As long as you get home in one piece (RFG, p. 68, L. 18).

> You risk your own [health] ... (RFG, p. 77, L. 17).

On call demands

This code relates to the recipient coordinators' concern regarding excessive on call commitments and the consequent long hours they are required to work. Four out of the five coordinators participating in the focus group interview were required to be on call whilst one participant had no on call commitments. Of the four who did, three were on call seven days per fortnight and one was on call fourteen days per fortnight:

> ... the on call demands were ... you know I think are quite unreasonable (RFG, p. 29, L. 28-29).

> ... there's a lot of on call and it's night work and it's day work ... (RFG, p. 72, L. 14).

Patients' lack of gratitude

Patients' *lack of gratitude* was discussed as a negative aspect of the recipient coordinators' role. However, the coordinators were sympathetic in realising that potential recipients are desperate and many will die without a transplant:

> ... having someone lying in a bed ... just had a transplant and in pain and [feeling] uncomfortable *'Oh God I wish I never went through this.'* And I feel like saying ... you've just received a ... ten-year-old child's kidney how can you lay there and say you wish you'd never had this ... (RFG, p. 35, L. 25-29).

Positive feedback

The following code reflects the experiences of the recipient coordinators in relation to positive transplantation outcomes. One coordinator stated that *positive feedback* makes all the effort, long hours and calls in the middle of the night worthwhile. Several coordinators gave examples of *positive feedback* they had received, most of which related to successful transplantations and recipients *'going back to their lives'*:

> ... the best feedback I've ever had is postcards from kids doing things that they never thought they'd be able to do again (RFG, p. 10, L. 13-15).

> ... I received a postcard from a lung transplant recipient; a postcard of Ayers Rock and all she wrote on it was 'I did it'. Now I knew exactly what that meant, that said it all, I ... didn't need anything else (RFG, p. 10; L. 19-22).

Power

The code *power* was a difficult concept to define within the context of the data from the focus group interview and this is reflected in the example given. However, the participant's quote does allude to a link between *respect, credibility* and *power.* With *credibility* comes *respect* and with respect there may be *power.*

> I suppose I've been around the place so long that they know who ... I am and also that I'm not going there with some frivolous little comment or frivolous question ... [there is] a reason for me doing it and there is some respect there. And there's also power in inverted commas but it's not power ... that you would have I don't think as an RN on the ward (RFG, p. 16, L. 28-31; p. 18, L. 1-3).

Recipient outcomes

There was agreement in this group that *recipient outcomes* are the main reason that coordinators are in the role. Seeing patients in end stage organ failure who would die without a transplant be given a second chance at life is an important aspect of the role. There are also *negative outcomes* that coordinators need to deal with as shown in the second example:

> ... I'm aiming to give somebody a better quality of life through some scientific or medical break through (RFG, p. 77, L. 8-9).

> ... I see two sides I have ... negative feelings when there's this poor outcome with the ... transplant and things go horribly wrong and ... your

> patient and ... their families are going through a terrible time (RFG, p. 35, L. 5-6; L. 11-12).

Relationships with donor coordinators

Relationships with donor coordinators were discussed mainly in conjunction with the organ donation and transplantation process. Recipient coordinators stated that it is important to them when organising a transplant that they have collaborative input into activities that involve them. The first example demonstrates that *relationships with donor coordinators* can be disharmonious. The other example from a participant offers some insight into the ambivalent relationship she has previously had with donor coordinators. However, she states that this has improved:

> ... if you feel that the donor coordinator is dictating everything *'you will do this you will do that ...'* theatre times are set for such and such without even hearing your side ... it's a two way street ... (RFG, p. 43, L. 10-13).

> I remember when I started I use to be traumatised by donor coordinators ... I find donor coordinators now a pleasure to work with. Occasionally I have a hiccup and invariably everybody is stressed or the circumstances are getting out of control from a number of perspectives. I mean there are times when I think God I'm not going pull this together (RFG, p. 47, L. 1-2; L. 6-10).

Relationships with health professionals

Recipient coordinators discussed both positive and negative aspects of their *relationships with health professionals.* Several comments related to understanding directors who unquestioningly signed off overtime. Another coordinator spoke of a director who organised additional staff when the workload increased within the transplant unit. There was agreement too that directors need to have some empathy with their staff. The recipient coordinators also appreciated health professionals who involved them in collaborative decision-making. In contrast other coordinators highlighted their frustration with medical staff who do not communicate important information:

> ... I'm very lucky because I've got a very understanding director ... (RFG, p. 73, L. 27-28).

> I'm very lucky that ... the consultant - the director of the unit will sign my time card no matter how many hours of overtime are on it and that's maybe due to a transplant or going in on weekends ... (RFG, p. 75, L. 27-30).

Relationships with recipient families

Recipient families appear to be an important group to the coordinators. The focus group participants affirmed the importance of supporting recipient families. This was particularly crucial to those who were involved in paediatric transplantation who reiterated that these families have a life outside the hospital environment and other children with needs too. Therefore health care should be facilitated in a way that not only accommodates the needs of the recipient but also that of their families:

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

Relationships with recipients

Throughout the course of the focus group interview there were many examples of the relationships formed between coordinators and recipients. Most were positive as shown in the example here:

> ... these patients can come to you ... before they go to surgeons, doctors, nurses anyone else, they come to you because they know they can trust you ... with anything they say and what you tell them will be ... the information that they need ... (RFG, p. 82, L. 26-30).

Respect

Respect appeared to be important to the recipient coordinators and they spoke of the *respect* they received from both colleagues and recipients. This code is also linked with *credibility* as is shown here:

> ... it becomes a nurse's dream to be respected and accepted as a colleague that knows what they're doing and... is respected for their decisions ... that you have the credibility ... (RFG, p. 80, L. 23-25).

Responsibility

Data that emerged in the code *responsibility* elaborated on the scope of recipient coordinators' practice and as the code name suggests, their level of *responsibility:*

> ... our role is ... huge ... in the unit like ours ... we put everybody on the list you know all the work up to the list, all that so ... the job is ... humongous and for ... only two coordinators ... it's hard work and ... not only that, you look after them post operatively in the clinic and you go on donor runs and all that sort of stuff so you're very busy (RFG, p. 24, L. 23-24; L. 27-31; p. 25, L. 1-2).

Seeing the process through

This code reflects the wishes of some coordinators that they follow the transplantation process through from beginning to end. However, this was not the case for others who believe the extended hours required to fulfil this commitment are far too long and thus an *occupational health and safety* issue:

> And I think that – yeah – that's part of the role of being a transplant coordinator for me that's part of the role that you start at the beginning and you see it through to the end (RFG, p. 65, L. 25-27).

Shared goals

The code *shared goals* reflects the recipient coordinators' belief that both themselves and the donor coordinators have *shared goals*, which involve the best use of organs and successful transplants:

> ...we both [recipient & donor coordinators] we all want the same outcome (RFG, p. 48, L. 2).

> I mean a person has died so therefore we want the best use of these organs that we can possibly get (RFG, p. 48, L. 6-7).

Standardisation

The recipient coordinators stated that one of the reasons coordinators are unable to obtain a degree of *standardisation* is because there are coordinators employed under different awards and from different professional backgrounds:

> ... we work under different awards and there's no standardisation ... nationally ... and the fact that ... the job requires clinical nursing experience but people can be employed without that so there there's a whole range of backgrounds which I think ... perhaps undermines ... you know it doesn't allow for standardisation (RFG, p. 66, L. 22-28).

Strong personalities

The example below is an indication that the organ donation and transplantation field appears to attract personnel with *strong personalities* to the role:

> In transplantation, you look around there's not one meek ... person in transplantation, should that be a surgeon, a doctor ... even the coordinators, you go to ... any meeting of coordinators and they're showing ... strong personalities. You have to ... be able to stand up for what you believe in ethics, morals surrounding what we do ... (RFG, p.40, L. 29-31; p. 41, L. 1-4).

Support people

The codes *support people* and *teamwork* are closely linked and in some cases interchangeable. Both involve the cooperation and interaction of colleagues and significant others. The subtle difference in these codes is that the coordinators talked about *support people* in terms of the emotional or more personal support they received from colleagues, family and significant others. In contrast, *teamwork* was discussed in a more collective sense, referring to the combined efforts of colleagues 'to get the job done' and the subsequent sense of accomplishment. The more personal nature of *support people* as discussed within the context of the focus group interview is confirmed in this example:

> ... the CNC on the ward I've developed a good relationship with and I can ... go off on a lunch break ... I can go and ... have a talk with her and off load ... (RFG, p. 34; L. 30-31; p.35, L. 1-3).

Teamwork

The code *teamwork* is reflected in the following examples. Several recipient coordinators indicated that *teamwork* is an important and fulfilling aspect of their role:

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

> ... the whole state team involved with transplantation ... medical and nursing wise ... were involved in making that decision (RFG, p. 14, L. 26-28).

The extra mile

The extra mile is a code reflecting the recipient coordinators' willingness to go *'the extra mile'* for patients and their families. In the context of the data given it appears that recipient coordinators are prepared to inconvenience themselves to accommodate or give extra assistance to patients and their families. Giving the patients a healthier life is their main objective:

> ... not just the emotional support, family support but there are little things that you can do for the patients ... (RFG, p.12, L. 16-17).

> ... I guess it's those little things, accommodating them ... (RFG, p. 12, L. 25-26).

Trust

The extracts below are two examples of *trust* as discussed by the recipient coordinators. The first relates to a coordinator's mistrust of using hospital health

professionals for formal *debriefing* or supervision. The next relates to recipient coordinators having to *trust* other health professionals; in this instance, donor coordinators to provide the *correct information* regarding the organ they are offering. One participant emphasised the fact that once the decision has been made to accept the organ there is little opportunity to retract:

> ... you've got to do it [debrief] outside the hospital because there's no way known you'd trust anyone inside (RFG, p. 33, L. 20-21).

> ... you're trusting somebody else to ... you know ... especially for ... I think for the transplants that once you're in ... you've gone (RFG, p. 61, L. 2-4).

Uniqueness

The coordinators in the focus group interview talked about the *uniqueness* of the transplant coordinators' role. All agreed that it is a specialised role and a unique area of practice:

> I would agree that our role is very unique actually (RFG, p. 21, L. 2-3).

> ... not just transplantation but transplant coordination is even more unique ... (RFG, p. 21, L. 16-17).

Use of skills

The coordinators discussed ways in which their skills were utilised in their role as recipient coordinators throughout the interview. This code is strongly linked to *autonomy.* As is evident here, it is the *autonomy* afforded to the coordinators that often enables them to use and develop many skills:

> ... new units ... that were established and we were the ones ... establishing you know coordinators in the units it means that you [are] the individual who's always got to introduce the innovation and you know carry it through (RFG, p. 30, L. 19-23).

Variety of people

Data that emerged in the code *variety of people* was discussed positively, with all coordinators stating that the *variety of people* and the diversity of cultures were all appealing aspects of the job:

> ... the variety of the people that we meet as a recipient coordinator (RFG, p 7, L. 24).

> It's just a whole variety of people that you get to know over the time, you know over the years and such like, which I think is really good (RFG, p. 7, L. 31, p. 8, L. 1-2).

Workload

The recipient coordinators believe that their role involves a significant *workload.* One coordinator describes how she feels frustrated at continually trying to catch up on work. The second example demonstrates another coordinator's perspective:

> ... an incredible workload and so what that leaves you with is a sense of ... frustration that you're all the time behind the eight ball ... catching up with workloads (RFG, p. 30, L. 6-9; L. 13).
>
> ... very high workloads ... (RFG, p. 30, L. 6).

The emergence of the preliminary categories

Following initial data analysis the codes and their contents were re-examined for further similarities or differences that had emerged between the codes. They were then grouped together to form preliminary categories through the following steps:

- Each code was re-examined to check that the data they contained was a true reflection of the code.
- Codes that were similar were then grouped together.
- These clusters then became preliminary or subcategories and were given a title that reflected the codes they contained.
- This process was initially done manually and then carried out using the NVivo software package for qualitative research. This two-tiered process provided a checking mechanism.
- In the process all the preliminary categories, subcategories and codes were constantly compared to check for ongoing emerging ideas, concepts, codes, categories, properties and links.
- During the above analysis memos were constantly written to assist in the process and provide information for future theory development.

Recipient coordinator focus group interview: preliminary categories

Five preliminary categories emerged from the recipient focus group and one of these had two subcategories as shown in Figure 5.1. This process of

aggregation involved many weeks of constant comparative analysis, whereby the researcher moved back and forth through the data in a cyclical manner looking for the emerging preliminary categories. The information in bold print indicates that the preliminary category, subcategory or code relates to information from the recipient coordinator focus group interview only. The non-bold print indicates that the preliminary category, subcategory or code is common to both the recipient and donor coordinator focus group interviews. The donor coordinator focus group interview is discussed later.

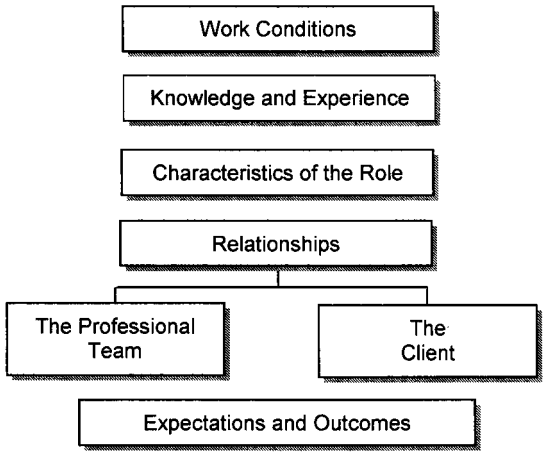

Figure 5.1: Overview of the preliminary categories and subcategories following the analysis of the recipient coordinator focus group interview data

WORK CONDITIONS

This preliminary category contained the codes *budget issues, making changes, occupational health and safety, on call demands, professional isolation* and *workload* as shown in Figure 5.2. The words, phrases or concepts represented in the codes had some connection to the recipient coordinators' WORK CONDITIONS. For example in the codes *budget issues* and *occupational health and safety* the coordinators discuss budget constraints in relation to overtime payments and the reluctance of hospital administrations to employ additional staff. When explaining the pressure one recipient coordinator experiences some days the tone of her voice in the interview suggests that the immensity of it made it difficult for her to articulate:

> They don't want to pay you ... there's no one else. Because that's the way the system's been set up ... not only that ... they don't even want to

> pay us, let me assure you ... pay us that overtime ... (RFG, p. 63, L. 9; L. 14; L. 16-18).
>
> ... your head would almost explode some days if you got two in a row [donor referrals] or you were doing [sigh] you had them all over the place that ... your head can almost explode with the amount of ... pressure that you've got to think about (RFG, p. 62, L. 1-5).

The other codes *making changes*, *professional isolation*, *on call demands* and *workload* were also grouped together in the WORK CONDITIONS preliminary category. They referred to other aspects of the WORK CONDITIONS as follows:

> You know I'd written letters ... talking about the burden ... the onerous task of being on call (RFG, p. 71, L. 10-11).
>
> ... you also work hard because you start from the beginning from pre-assessment, you become the resident on the ward when they [transplant recipients] are immediately post op or I do, checking things left right and centre (RFG, p. 26, L. 3-6).

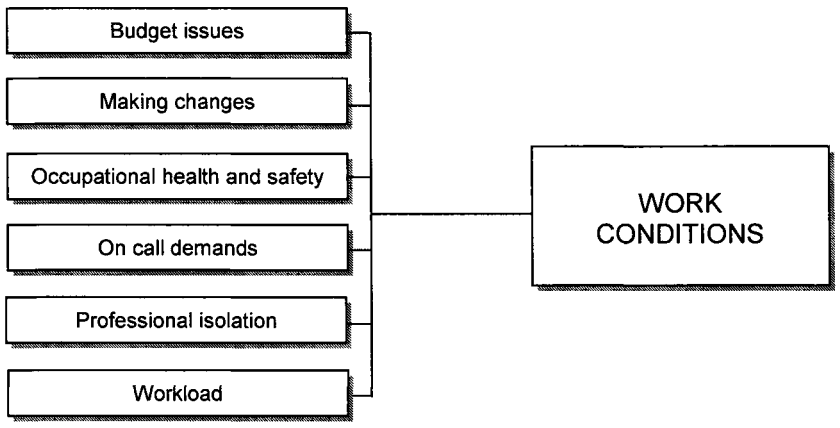

Figure 5.2: Preliminary category - Work conditions

KNOWLEDGE AND EXPERIENCE

This preliminary category incorporated the codes *education, experience, knowledge, use of skills* and *nurse - non-nurse* as shown in Figure 5.3. The code *nurse - non-nurse* contained two sub-codes – *correct information* and *standardisation;* all had some reference to KNOWLEDGE AND EXPERIENCE as follows:

> ... it would be best if they were a trained nurse ... (RFG, p. 55, L. 13-14).
>
> ... to have ... knowledge ... (RFG, p. 47, L .29).
>
> ... you're not developing on something that has already been established but you're the one that is establishing the policies ... (RFG, p. 30, L. 27-29).

The code *nurse - non-nurse* relates to what educational qualifications transplant coordinators should have and how non-uniformity of qualifications presents ongoing challenges to standardisation. The recipient coordinator focus group provides the following examples:

> ... the person relating the information to me was not a nurse ... (RFG, p. 7, L. 2).
>
> So correct information I think is imperative (RFG, p. 8, L. 16).

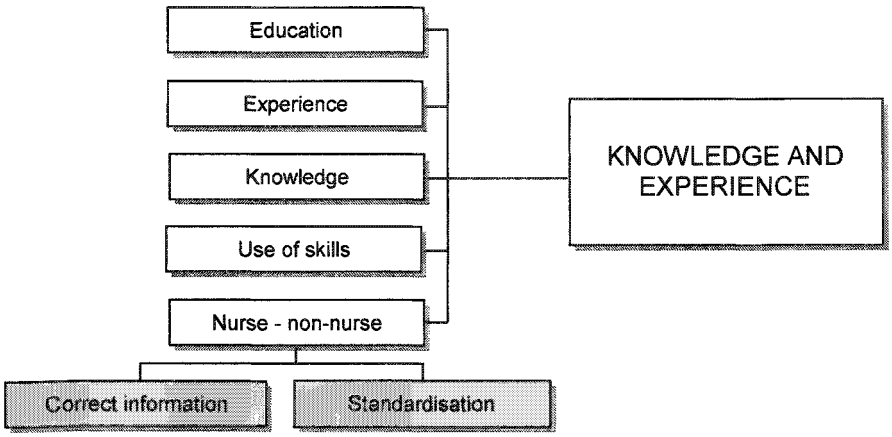

Figure 5.3: Preliminary category - Knowledge and experience

CHARACTERISTICS OF THE ROLE

This preliminary category entailed the codes *advocacy, autonomy, credibility, job satisfaction, power, respect, responsibility, strong personalities, variety of people* and *uniqueness* as shown in Figure 5.4. These appear to be the elements that attract and keep recipient coordinators in the job. Examples of information that emerged include:

> ... I've got more power ... (RFG, p. 16, L. 1).
>
> ... the respect that you get from your colleagues ... (RFG, p. 2, L. 24-25).
>
> ... you know what the patient needs and you just go ahead and do it (RFG, p. 18, L. 4-5).

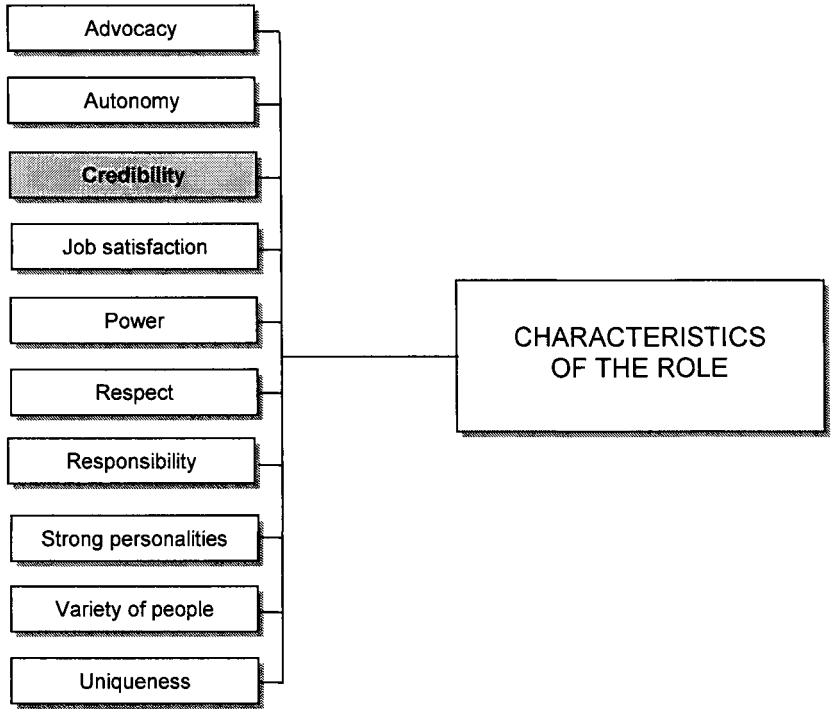

Figure 5.4: Preliminary category - Characteristics of the role

RELATIONSHIPS

This preliminary category contains two subcategories, *THE PROFESSIONAL TEAM* and *THE CLIENT,* which relate to recipient coordinators' relationships. The first addresses their relationships with colleagues and health professionals they work with. The second involves the relationships with clients and their families.

THE PROFESSIONAL TEAM

The codes contained in this subcategory include *communication, compromise/flexibility, debriefing, difficulties with doctors, frustration, learning others' role* (donor coordinator's role), *relationships with donor coordinators, relationships with health professionals, shared goals, support people, teamwork* and *trust* as shown in Figure 5.5. They contain similar information about the professional team and highlight how the team operates, who is in it, difficulties experienced, shared goals, how they support each other and available debriefing avenues.

During data analysis the following examples emerged and were placed in codes which were then clustered together in the subcategory *THE PROFESSIONAL TEAM:*

Yes they [doctors] can't decide what they want; they change their minds all the time (RFG, p. 27, L. 19-20).

... it's being understanding ... [of] each others [donor and recipient coordinators] issues and the only way perhaps you can have that understanding is to have a knowledge and ... going and doing their job with them on one occasion or visa versa I think would increase that knowledge (RFG, p. 47, L. 27-31).

... we work really well together [recipient & donor coordinators] because we know what's going to come up next (RFG, p. 49, L. 27-28).

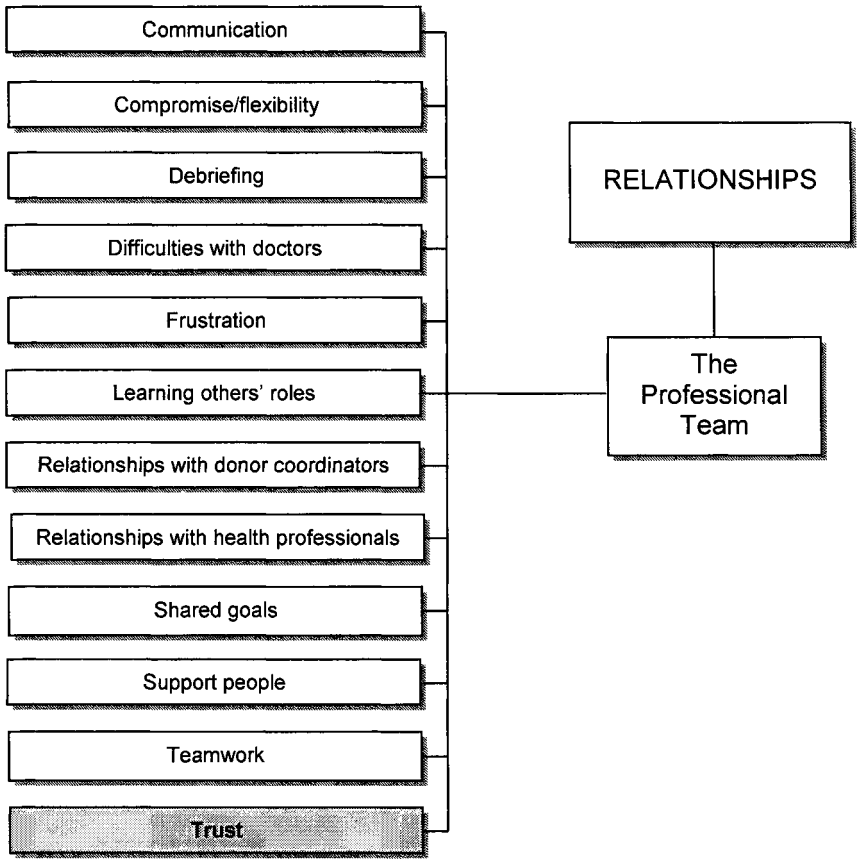

Figure 5.5: Preliminary category - Relationships and the subcategory - the professional team

THE CLIENT

The codes contained in this subcategory refer to the recipient coordinators' *relationships with recipients*, *relationships with recipient families* and going *the extra mile* as shown in Figure 5.6. Similar codes were clustered together to form the subcategory *THE CLIENT*. Two examples that contributed to its emergence are shown below:

... I like seeing them survive. I like seeing them ... wander out the door and ... send me a card or ring me up and give me cheek or whatever. [Laughter]. I love that ... (RFG, p. 79, L. 2-4; L. 10).

... to be able to make a difference in these people's lives ... (RFG, p. 81, L. 13-14).

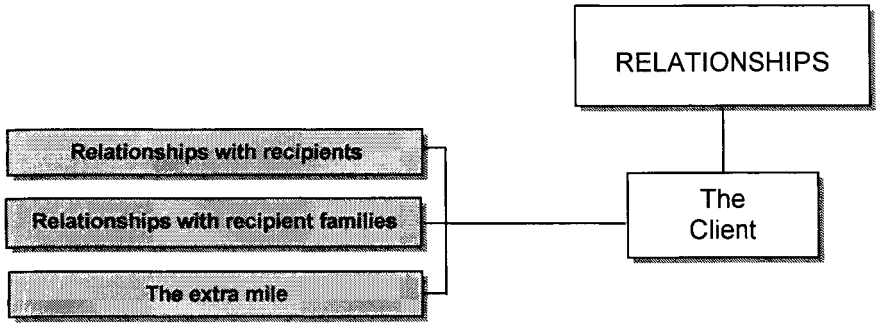

Figure 5.6: Preliminary category - Relationships and subcategory - the client

EXPECTATIONS AND OUTCOMES

This preliminary category entailed the codes *going back to their lives, negative outcomes, patient's lack of gratitude, positive feedback, recipient outcomes* and *seeing the process through* as shown in Figure 5.7. All of them related to the expectations of clients, families and health professionals in regard to outcomes. Some examples from the recipient coordinators reflect positive outcomes whilst others allude to *negative outcomes*:

... all you need to see is one person with a smile on their face because they've got ... their new organ and we've ... just literally saved their lives ... (RFG, p. 22, L. 18-20; L. 24).

... otherwise we lose organs (RFG, p. 44, L. 13).

To give ... the parents back their daughter or son is just that you know, it's priceless really (RFG, p. 23, L. 11-12).

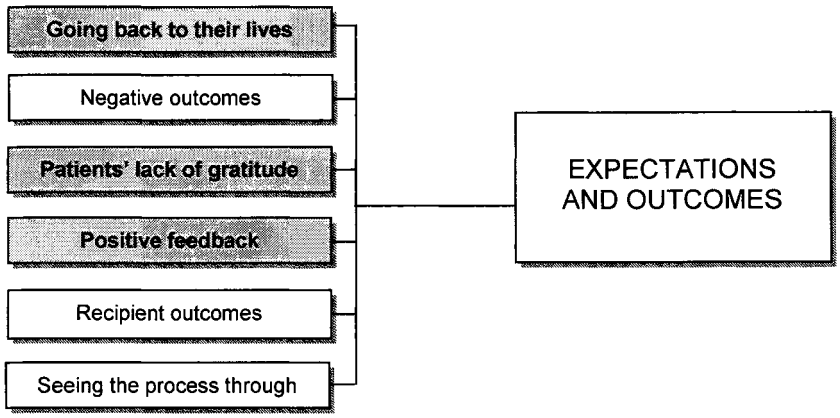

Figure 5.7: Preliminary category - Expectations and outcomes

A description of how open coding was used to constantly compare and analyse data from the recipient coordinator focus group interview has just been detailed. Examined were the codes, subcategories and preliminary categories that emerged from the data. Five preliminary categories emerged:

1. WORK CONDITIONS
2. KNOWLEDGE AND EXPERIENCE
3. CHARACTERISTICS OF THE ROLE
4. RELATIONSHIPS
5. EXPECTATIONS AND OUTCOMES.

Figure 5.8 gives an overview of these codes, subcategories and preliminary categories. This is followed by an analysis of the donor coordinator focus group interview data.

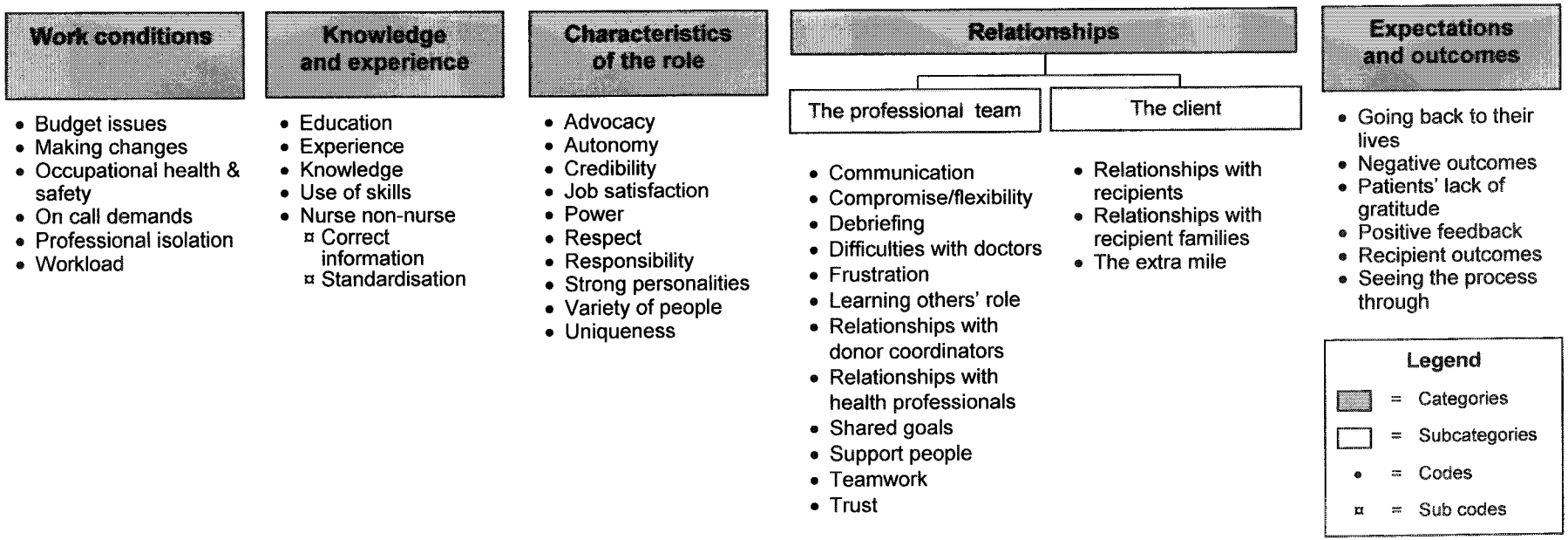

Figure 5.8: An overview of the codes, sub-categories and preliminary categories following analysis of the recipient coordinator focus group interview data

Donor coordinator focus group - open coding

Constant comparative analysis of the donor coordinator focus group interview data will now be examined. This involves a comparison of the codes, subcategories and preliminary categories that emerged from this interview with those of the recipient coordinator focus group interview. Emerging codes from the donor coordinator interview are discussed as are the shared codes that developed from both groups.

Following open coding fifty-five codes were identified from the donor coordinator focus group interview data (Appendix 28). Thirty-four of these codes were the same or similar to those of the recipient coordinator focus group interview; they were shared codes (Appendix 29). Thus ten codes were recipient coordinator-specific (Appendix 30) and twenty-one were donor-coordinator specific (Appendix 31). In total there were sixty-five codes following the constant comparative analysis of both interviews as shown in Figure 5.17 on page 152.

As with the first focus group interview there was considerable overlap between the codes that emerged in the donor coordinator focus group interview also. These codes are discussed below and examples are provided.

Bad behaviour

The code *bad behaviour* emerged from the data in the donor coordinator focus group interview. It indicates that *bad behaviour* is a part of the culture in which donor coordinators practice. Coordinators discuss instances of bad behaviour that they have witnessed or experienced. One recalls a situation involving an ICU consultant who was unwilling to explore the option of organ donation for a family. The coordinator considered the consultant's behaviour to be unacceptable:

> I had one ICU consultant where the family wished to donate and there were a number of issues ... surrounding the medical suitability and ... what happened was that this ICU intensivist withdrew consent. He saw it as his right to withdraw consent from the family to proceed with the donation ... despite my ... discussions with him ... (DFG, p. 32, L. 7-12).

> ... it floored me to see the walls of silence that could exist within medical units ... to cover people's bad behaviour and I'll term it bad behaviour (DFG, p. 31, L. 15-18).

Bullying, put-downs and undervalued

The examples in this code highlight the type of *bullying* and *put-downs* as experienced by some donor coordinators. Participants believed that *bullying* is an indication that donor coordinators are at times *undervalued* professionally and personally:

> ... I remember when I started with my congratulations came, come into my office and then sit down [doctor's office] and it was 'well [name of coordinator] what do you really want to be when you grow up?' (DFG, p. 37, L. 15-18).

> ... I've had occasions where I've contacted [medical] people in the middle of the night and been told to [offensive language] and 'I'll get you' and 'you'll do what you're told'...and all that kind of stuff ... there are people [doctors] that are not at their best at certain times and still ... want to be on call twenty-four hours ... and so you have to ... I suppose deal with a lot of I think aggression sometimes ... (DFG, p. 42, L. 30-31; p. 43, L. 1-5).

Care of donor families

Care of donor families is a central part of the donor coordinator's practice. There were several examples highlighting the importance of giving donor families adequate and *correct information,* so they could make informed decisions regarding organ donation. Other aspects of donor family care that were discussed included family support and ongoing care in the short and long term:

> So I saw that as my role, to empower them at a time that people would perceive that the family couldn't be empowered at all (DFG, p. 8, L. 1-3).

Challenges

The code *challenges* reflects the participants' belief that their role is challenging as articulated:

> ... challenge certainly came into it and autonomy I mean I think together [challenge and autonomy] they both made up a very ... important part of the role for me ... (DFG, p. 5, L. 22-24).

Competition

The *competition* code emerged solely in the donor coordinator focus group interview. It demonstrates concerns with destructive aspects of *competition* as well as the perceived increase in competitive behaviour in their practice:

> ... when I started I was sharing an office with the other coordinator in the state and we were a very ... streamlined ... quite effective agency and we've moved into a glossy office and now we've got to justify our existence and the politics is rife and the competitiveness between

> individuals and states nationally even ... internationally is ... certainly something that ... is increasing dramatically ... (DFG, p. 21, L. 6-12).

> At present the culture requires that all coordinators strive to be 'superwoman' or 'superman' - to stay awake the longest, coordinate the most donors, retrieve the most organs, write the most papers, etc. (DFG, p. 1b).

Control issues

One participant describes her feelings of lack of *control* over her life and the resulting unhealthy anxiety levels:

> ... I'm someone who likes to have some control over their life that likes to be able to plan and being on call all the time takes that away from you, you can't plan and ... I found I was at the point where I was jumping out of my skin when the phone rang every time ... and ... that's not healthy (DFG, p. 25, L. 26-30).

There was also a view that doctors do not confront issues in the organ donation and transplantation field if they are unable to *control* the outcome, choosing instead to avoid these areas of conflict:

> It's the fact that the medical system can't control the outcome and there's a high risk involved so the best avenue is to choose to do nothing (DFG, p. 34, L. 22-24).

Donor family – recipient contact

Donor families and recipients having *contact* with each other is an issue that generates much debate. Shown below are two of many views about this. The second example confirms that there are legal implications regarding such contact:

> The issue relating to donor families and recipients meeting everybody knows [it] is complicated, there's no doubt about it ... (DFG, p. 34, L. 13-15).

> ... there are different views based on different legal interpretations on donor family contact [with recipients] that makes things a little bit difficult ... (DFG, p. 23, L. 28-30).

Expendability

An issue of concern for the donor coordinators is that of *expendability.* Several believed that they are seen as expendable, perceived as temporary workers who will move on to other occupations. They feel there is an attitude within the organ donation and transplantation fraternity that they will leave and there will be others to replace them. This attitude they assert impacts on other aspects of their role

such as their ability to have a voice, an opinion or input into their area of service delivery:

> ... while we're in the job ... we have good relationships with ... various people but we're seen as being disposable (DFG, p. 38, L. 13-14).
>
> Yeah very expendable and therefore it is hard for us to have a say because we're still seen as being someone that might not be there in a year's time (DFG. p. 38, L. 18-20).

Inequity in funding

The code *inequity in funding* relates to the view of some that funding used to care for donor families post-donation is seen as a 'soft' expenditure. They believe there is inequity in funding for donor families in comparison with that of large ICUs in two states, who receive funding to cover the cost of maintaining potential organ donors. They also believe that donor family care is not seen as being equally important and therefore does not receive the funding required:

> I find it difficult to accept that we can allocate a ... I'm just going to choose an arbitrary figure and say a thousand [dollars] towards ... if you like compensating a unit for the ... resources that are required to support a donor but we can't support a donor family, we have to argue for that or ... it's seen as a soft kind of ... expenditure it's not recognised as being equally important or that there needs to be a battle in order to have it recognised as being equally important ... (DFG, p. 30, L. 1-4; L. 8-12).

Intimacy of the job

Several donor coordinators spoke of what they referred to as the *'intimacy of the job'*. One who had recently resigned shared her thoughts with the focus group explaining that although she would miss the *intimacy of the job*, it was that which made her grateful she had left. Another coordinator reinforced this sentiment:

> ... what I miss and there's ... a conflict here, I miss the intimacy the intense intimacy that can exist in those situations but that's the very same factor that actually makes me grateful that I'm not there anymore because it [the job] can be so taxing and so taking from you (DFG, p. 14, L. 9-12; L. 16-17; L. 21).
>
> ... intimacy is certainly ... a real attraction to the job but something that can destroy you at the end. I mean the job, at the end I think ... does ... take ... literally your soul away ... (DFG, p. 15, L. 1-3; L. 6-7).

Lack of acknowledgement

One donor coordinator discussed the *lack of acknowledgement* received from within the system. She discussed how the demand for organs would always outstrip supply and believes that most coordinators around Australia and New

Zealand are doing their best under difficult circumstances. This is not always acknowledged and coordinators are often the last ones to receive support:

> ... I think generally all the states are doing very ... well and trying their hardest in a very tough situation and ... sometimes that is over looked and I think a lot of the time the bureaucracy perhaps forgets the people that are working in its system and for such a caring system I think a lot of the time the coordinators [are] the last ones that get a pat on the back ... that get any support ... (DFG, p. 22, L. 4-10).

Lack of consensus

The inability to gain *consensus* on a number of national projects and visions, such as whether or not donor families and recipients should meet, was difficult for some donor coordinators. It was also felt that this was an impediment to moving forward in a number of areas:

> ... frustration with the incredible difficulty of getting a national consensus (DFG, p. 22, L. 28-29).

> ... coming to a consensus where you could actually move forward with some issues I think you know was ... challenging ... (DFG, p. 23, L. 3-5).

Leaving the job

Two coordinators stated why they had either left or were *leaving the job* and whether or not they would miss the role. There is a sense of loss but also an element of relief reflected in their words:

> There was a real sense of completion that you don't normally get to have and I think ... I'm going to miss that. As well as those very ... close relationships both with your colleagues and with ... the other staff because it's ... a very ... powerful ... experience for everybody ... organ donation ... and the actual retrieval and ... I think you just don't get to relate to people ... in that way every day ... (DFG, p. 12, L. 16-18; L. 22-27).

> ... I was just very ready to leave ... and ... I think that's because you know of the on call and all that sort of stuff (DFG, p. 11, L. 25-27).

Non-supportive colleagues

In this code coordinators discuss the difficulties arising when there is little or no support from colleagues. For some it meant being unable to contribute in a meaningful way, for another it lead to feelings of isolation in her own state. Fortunately, she was able to seek out alternative avenues of support from colleagues elsewhere around Australia and New Zealand:

> ... there are definitely feelings amongst my colleagues and myself ... that there is ... a large degree of non-support or inability at times to provide

> input into issues [regarding] organ donation and transplantation (DFG, p. 36, L. 21-25).

> ... I invested a lot of time and energy into that relationship to ensure that it would be positive ... I had walked into a situation ... where that individual already felt quite negative because of ... past history ... but I could only sustain that to a certain point ... and I didn't have a ... supportive relationship with my colleague so that's the honest truth of it ... (DFG, p. 44, L. 3-8).

Organ donation a business

For some coordinators the fact that organ donation was run as a business was an anathema and incongruous with the concept of altruistic giving. They felt the usual principles of business were difficult to apply as organ donation and therefore transplantation relied solely on the goodwill of the public. This code is closely linked to the code *inequity in funding,* which in part sheds light on the following expressed concerns. Some coordinators believe that it is due to a business approach that donor families may not be receiving adequate support. The fact that donor family support is perceived as a 'soft' expenditure also does not 'sit comfortably' with donor coordinators:

> ... I think they are trying to run organ donation as a business and I think when you're relying on ... people donating and the altruistic view that is shared ... within this country you can't run organ donation as a business ... (DFG, p. 21, L. 16-20).

> ... the normal concept of a business unit isn't fully applicable ... (DFG, p. 28, L. 27-28).

Others knowing best

A code pertinent to the donor coordinators was *others knowing best.* Several examples emerged of circumstances where others had presumed they knew what was best for the donor coordinators. In most of the examples the 'other person' referred to was a medical practitioner:

> '... well, if you're still here in five years I would really have to worry about you wanting to stay in this job for five years, I don't see it as being a long term career' and that came from the person that had just employed me (DFG, p. 37, L. 18-22).

> ... it was my on call week but the [other coordinator] came in to ... assist me and ... the surgeon said to me, 'Well you've seen one isn't that enough, why are we paying for two people being on call,' that was the comment. And ... my response was that as far as I was concerned I was well and truly on L plates and I wouldn't put other people at risk but that ... was the attitude (DFG, p. 40, L. 31; p. 41, L. 1-3; L. 7-9).

Outcomes – donor family

Donor coordinators like recipient coordinators were concerned about outcomes for their client group, in this case donor families. Positive outcomes for families were a significant challenge for the coordinators. Not only were they concerned with donor family care in the organ donation process but also the longer term input for the families, their advocates, donor coordinators and intensive care specialists. This is reflected in the second example highlighting how important it is for those involved in organ donation to have an equal say and not have the transplantation fraternity dominating the decision-making processes:

> How can you be empowered in the context of death and ... pain and grief and so forth? So I took that on as my role to give them [donor families] as much ... I felt good, if I believed that I had given them as much control and as much information and ... as much opportunity to know that they did everything they could and that they would hopefully not have any regrets about the situation ... (DFG, p.8, L.7-13).

> ... it is very ... important for donor families and for ICUs and for public perception that that is constantly evened out with input from [pause] donor coordinators, donor families and also the intensive care staff. But I think it's a constant battle to ... achieve that balance (DFG, p.36, L.10-15).

Political-bureaucratic issues

The code *political-bureaucratic issues* originated from a question in the focus group interview, which enquired about negative issues that impact on practice. Several views indicated that the area of organ donation and transplantation is political and bureaucratic in nature with significant self-interest displayed by many. However, one coordinator stated that this is not transplant coordination or coordinator-specific as political and bureaucratic issues are essentially a part of all areas of employment:

> Politics, bureaucracy ... that occurs in any public health care system (DFG, p. 17, L. 2-3).

> ... I have to say ... I don't think it's specific [political issues and people's self interest] to this ... particular job or role ... you will find it in which ever job you go to ... that's my experience anyhow (DFG, p. 17, L. 11-14).

Relationships with donor families

The *relationships* donor coordinators have with donor families are very important to them. They demonstrate that not only is the initial *relationship* with families at the time of organ donation important but also the longer-term professional *relationships*, which may develop with donor families. The second example also

gives an insight into the impact that donor families can have on donor coordinators:

> ... it was quite a privilege to be able to deal with people at that time in their lives and to be able to follow that through and you know to form ... relationships I suppose on a professional level with ... donor families and that was very ... rewarding as well (DFG, p. 6, L. 24-28).

> ... I actually felt that each and every time I worked with a donor family ... that I took something away from that by way of personal growth in terms of dealing with the individuals ... for me I always felt that there was a level of personal growth from ... each exposure to a donor family ... (DFG, p. 8, L. 14-17; p. 9, L. 12-14).

Relationships with recipient coordinators

There appears to be genuine respect and understanding amongst donor coordinators for their recipient coordinator colleagues, which is reflected in the examples. Two coordinators in the focus group, however, were unable to comment as they felt they had limited interaction with recipient coordinators:

> I think that the transplant colleagues [recipient coordinators] that I've ... worked with have all been ... terrific people who ... have been very generally interested in ... doing a good job but are often dealing with ... equally or even more difficult circumstances than ... we are on the donation side of things (DFG, p. 46, L. 20-24).

> ... the recipient coordinators generally are ... wonderful, fantastic [people] and we work together very well ... (DFG, p. 47, L. 15-16).

Voice not heard

This code highlights the frustration that some donor coordinators feel in regard to not having input into decision-making processes which they believe affect them, their client group or their practice:

> ... every day there was the potential to be left out [of decision making] and ... I think a lot of the time transplant and donor coordinators are left out unless they muscle their way in (DFG, p. 35, L. 30-31; p. 36, L. 1-2).

> ... the other thing that was really difficult was in the dealings with government on certain issues and ... government appointed bodies that dealt with organ donation ... having your voice heard ... no matter how well researched that voice may be ... trying to ... have some meaningful input into some of the decisions that were made ... it felt a lot of the time that it was just ... lip service ... being given to ... different points of view and different arguments ... (DFG, p. 23, L. 5-13).

There were codes common to both groups. The donor coordinator focus group now provides the following examples of these codes.

Advocacy

Donor coordinators believe that part of their role as a coordinator is to be an advocate for donor families:

> ... how I viewed the role was that I was ... possibly one of the only ones who could empower the family at that point in time (DFG, p. 7, L. 30-31; p. 8, L. 1).

Autonomy

This code emerged from both focus group interviews. The thoughts from the donor coordinators' group are documented in the following examples. The first participant discusses *autonomy* as being one of the strengths of the position. The second is more 'guarded' in her comment, stating that there are some restrictions to the level of *autonomy* coordinators are given:

> ... I certainly agree with the issue of autonomy, I think that was one of the strengths of the position and probably ... made it a viable position. It would have been very difficult to have done ... otherwise (DFG, p. 7, L. 26-29).

> ... so even though we're quite autonomous it's only really up to the level that people want to give us our autonomy (DFG, p. 39, L. 16-18).

Budget issues

The main focus of this code related to having enough money to support donor families. The first example gives some insight into this. The second example refers to financial remuneration for coordinators' overtime and support services for donor families. There is considerable overlap between this code and the code *inequity in funding:*

> I can't say how much it use to annoy the [offensive language] out of me to put it really simply how there would be a budget for the purpose of ... retrieval, there would be budgets for the purpose of ... a variety of things as they related to transplant ... when you go into ... the argument, of arguing that donor families require certain services ... we believe that a budget of fifty dollars per family will cover the acknowledgement services, books, pins ... etc ... that's frowned upon, suddenly the ... cost of fifty dollars per family is seen as ... excessive (DFG, p. 28, L. 28-31; p. 29, L. 1; L. 8-9; L. 16-18; L. 22-23).

> ... there are managers now that look at bottom dollars that want to cut overtime, that want to cut support services to donor families ... (DFG, p. 21, L. 20-22).

Communication

Communication also emerged as a code in the donor coordinator focus group interview. The first example given reflects the positive aspects of *communication.*

The second highlights how poor *communication* can hinder the donation and transplantation process, particularly when information has to be passed through a number of people in the system:

> ... as individuals I feel all the coordinators communicate really really well ... (DFG, p. 22, L. 30-31).

> ... in regards to things like...tests and things that they [coordinators] require and that type of thing they ... can cause issues because it comes [sigh] through three people ... before it gets back to the actual bedside area ... so communication can quite often cause... a hindrance to the actual process ... (DFG, p. 18, L. 12-17).

Compromise/flexibility

In this code the donor coordinators discuss their experiences in relation to compromise and flexibility. One extract describes how a donor coordinator tried unsuccessfully to negotiate a compromise with a colleague in relation to an earlier 'hand over' time. The other example emphasises the importance of progressing the organ donation process for the sake of the donor family, staffing and bed availability in the ICU or due to donor instability and the subsequent risk of losing organs through delay. However, the participant is also mindful of the need to be flexible and aware of the dilemmas her colleagues may be facing at the time of donor referral:

> Normally if we start with the donor, we'd finish with the donor so that was the best I could get [the coordinator] to compromise was to come in ... when the patient was ready to go to theatre (DFG, p. 45, L. 9-12).

> ... we have our twenty-minute rule [recipient coordinators have twenty minutes to notify the donor coordinator if the transplant unit is accepting or rejecting the offer of an organ]. You know we created [it] for very ... good reasons ... but I ... found you know sometimes that I had to try and lay down the law for the sake of ... keeping the process going for the donor family and the ICU [side] or instability [of the donor] but I ... tried to be as fair as I could and as flexible as I could because I knew that a lot of the time they ... [recipient coordinators] were just being screamed at ... by a transplant surgeon or physician, or they couldn't actually find anybody to ask ... (DFG, p. 46, L. 1-2; L. 6-13).

Debriefing

The examples in this code describe the demanding nature of the role and the need for coordinators to 'recharge their batteries'. This is necessary for them to continue functioning at a reasonable level and maintain their own mental health. There is an implied message that adequate *debriefing* opportunities may be unavailable or unsuitable. It generates the issue of why coordinators feel they are unable to 'recharge their batteries':

> ... I think you need time when you're dealing with death and dying every day you're dealing with all these powerful emotions you need time to recharge your batteries (DFG, p. 27, L. 24-27).

> ... we're talking about the politics and all that sort of thing; you can deal with that if ... you've had a chance to recharge your batteries. But I found that I wasn't ... getting a chance to recharge my batteries (DFG, p. 27, L. 28-30; p. 28, L. 3).

Difficulties with doctors and nurses

The following examples reiterate the difficulties coordinators can have with other health professionals. In the first example a donor coordinator describes a situation that has the potential to put the donation and transplantation process in jeopardy if team members are not prepared to work together. In the next example a coordinator describes how she has had good support at a state level but at the local level health professionals are less interested in what she has to say about organ donation and transplantation. This in turn makes it difficult to educate staff about issues relating to the field:

> ... one surgeon might not be working towards a ... team approach so ... might take excessively long to do what is their responsibility i.e. perhaps their opening up and ... they may be removing ... the kidneys or the liver and they know that there's a plane that has to take off at a certain time with the lungs ... and they've ... got there late to the hospital and they're going a little bit slower than what you want them to. And ... they don't see it as their issue they don't see it as their problem, that's the ... cardiac team's problem ... And ... I found that really difficult because I could see, you know it was obviously getting the ... recipient team ... the heart and the lung teams very stressed and very angry and rightly so (DFG, p. 48, L. 20-29; p. 49, L. 2-5).

> ... it's hard to get anyone interested and I don't know whether that's just a sign of the times in public hospitals at the moment but no one seems to be interested in learning anything or participating in anything new or even ... have their mind open to anything new at all. So health care professionals have been ... one of my 'bug bears' (DFG, p. 19, L. 4-9).

Education

In comparison to the recipient coordinator focus group interview data the issue of *education* appeared to be less of an issue for the donor coordinators. However, one did mention her concern about the training transplant coordinators receive as shown in the first example. Others discussed the length of time required to achieve a level of competence in terms of the practical aspects of the role in particular the organ donation process. This is difficult to quantify as it is largely dependent on the number of organ donors that occur within the coordinators' practice. This varies considerably between countries and from state to state:

> ... I suppose my concerns always been the training ... (DFG, p. 5, L. 11).

> To be competent depends on the time and experience within the job. Twelve months or six donors as a minimum. Even so you never stop learning (DFG, p. 41).

Experience

The code *experience* referred to how much the coordinators learnt during their time in the role:

> ... I've learnt so much over ten years that perhaps people that work for fifty years might never experience ... (DFG, p. 4, L. 11-13).

Frustration

This code refers to the *frustration* the donor coordinators appear to have over the lack of common direction and the absence of a manager within an organisation as shown in the examples. There were other areas of *frustration* some of which related to *inequity in funding*, people's self interest, game playing and politics, health professionals' perceived lack of interest in the area, long hours, running organ donation as a business and the paternalistic attitude within the health system. Therefore there is considerable overlap between the code *frustration* and others that discuss a number of these issues in more depth:

> ... trying to get a common direction amongst the state, as a whole is extremely frustrating ... (DFG, p. 17, L. 21-22).

> ... type of things I find most frustrating ... as ... mentioned before, not having a manager ... for a ... long period ... has been extremely difficult ... (DFG, p. 17, L. 18-21).

Job satisfaction

Like the code *job satisfaction* that emerged from the previous focus group interview there were many examples in this second focus group interview, which were also placed in this code. Unsurprisingly, there was also significant overlap between this code and other codes:

> ...I love my job (DFG, p. 3, L. 23).

> ... a job that is very challenging and rewarding ... (DFG, p. 4, L. 8).

Knowledge

There was some discussion in the donor coordinator focus group interview in regard to *knowledge* and how the need for *knowledge* is changing with the role. One coordinator elaborates on this view in the first example. The other example highlights the quantity of *knowledge* that coordinators believe they have:

> ... if anything it's changed to the fact now that you need a certain level of knowledge because there is so much you need to do so many forms you need to fill out so many legal considerations ... that now I think ... the knowledge level is ... getting to the stage where we're becoming entrenched and it's ... hard to find anyone that's willing to accept the responsibilities of the role (DFG, p. 5, L. 1-8).
>
> ... we have a huge knowledge base ... (DFG, p. 39, L. 9).

Learning others' role

As was the case with the recipient coordinators, donor coordinators also discussed their beliefs in relation to understanding their colleagues' role. The donor coordinators' views were not articulated as clearly as their counterparts. They did not appear to want to participate in or be an observer in the transplantation process as was the case with the recipient coordinators, who were keen to experience the donor coordinators' role first-hand. One coordinator stated that all coordinators are equal and that the roles are both difficult but different:

> But generally I think we do understand each other very well, we're both working for a similar good ... (DFG, p. 47, L. 27-28).
>
> ... I think recipients' coordinators have a ... difficult job and ... its just as difficult in some ways [as the donor coordinators' role] but ... different (DFG, p. 48, L. 11-13).

Making changes

There was some discussion amongst the coordinators in regard to *making changes.* They acknowledged that the role gave them the opportunity to work closely with government officials and in some way influence outcomes. In contrast one of the participants clearly articulates what she sees as the main impediment to *making changes:*

> ... you're working ... quite closely with the Department of Health and ... with other officials and you really got a chance to see how things worked ... and to get a chance to in your own little way influence things, which again you never had the opportunity to do in the hospital setting (DFG, p. 6, L. 14-17; L. 21-22).
>
> I believe the biggest challenge in achieving the necessary cultural change is overcoming the fear that reducing the stress or the expectations placed upon coordinators will somehow reduce the 'special ness' the 'exclusivity' or importance of the role (DFG, p. 1b).

Negative outcomes

Negative outcomes is a code that was discussed within both focus group interviews. In contrast to the recipient coordinators who discussed *negative*

outcomes in terms of failed transplants or lost organs, the donor coordinators did not discuss *negative outcomes* in a life or death context. Donor coordinators talked about health professionals who are not prepared to participate in education sessions or having to tell a family that organ donation would not be proceeding because the doctor had decided to withdraw this option:

> ... I really feel strongly about [organ donation] and have put a lot of work into it and then to have people ring and say oh no we don't want you to come and teach us about organ donation or brain death ... we haven't got time for that and yeah so there it's pretty disappointing ... (DFG, p. 19, L. 18-22).

> I found that so difficult that I had to go and tell the donor family he [the doctor] wouldn't do it, that the donation wasn't going to proceed. Why wasn't it going to proceed? I didn't lie to them I told them the truth (DFG, p. 32, L. 24-27).

Nurse - non-nurse

Non-nurses who practice as transplant coordinators were a significant issue for the recipient coordinators. Many believe that they lack the *knowledge* to perform some aspects of the role, particularly with respect to the organ donation and transplantation process. Donor coordinators did not appear to hold this view and spoke of non-nursing coordinators needing extra time to learn the role and ongoing support from their colleagues:

> ... not having had any health background created a ... situation where I needed my colleague, it was as simple as that ... you know I needed that person to help me ... receive my training ... and to be there on the ground until I had enough experience under my belt to do it by myself (DFG, p. 43, L. 29-31; p. 44, L. 1-3).

> So I found that really difficult ... in the sense of and perhaps this is again coming from a non-medical background ... (DFG, p. 33, L. 18-20).

Occupational health and safety

The *occupational health and safety* issues that appeared to be inherent in the role and were most problematic to donor coordinators were excessive on call requirements, long work hours and subsequent lack of sleep. These issues are strongly articulated:

> ... the physical demands of the role from an occupational health and safety perspective are significant, I find it astounding that the needs, the occupational health and safety issues can be completely ignored when it comes to donor coordinators, in which role would it be acceptable that you are working [on call] twenty four hours a day seven days a week, my case it was one week in two (DFG, p. 30, L. 14-19).

> ... that it's ... OK for them to work perhaps start working [at] nine o'clock or eight o'clock [in the morning] one day and not finish until four pm the next day not have gone to sleep and that's fine! And in fact there might actually be a question as to why you weren't at work the next day at nine am (DFG, p. 30, L. 28-31; p. 31, L. 1-2).

On call demands

On call demands was another shared code. For coordinators with job descriptions requiring the performance of on call duties, there was much discussion and angst about its excessiveness. The continual expectations to increase on call commitments particularly when staff are on sick, conference or annual leave was also unsatisfactory to a number of participants. The examples are a small selection of the discussion points concerning this matter:

> ... I started to find the on call extremely onerous ... I found ... in the last six months I started to find it increasingly impossible to achieve, you know, a healthy balance in my life between work and ... everything else (DFG, p. 24, L. 26-30).

> ... and then put me on [call] for two and a half years with out a day off (DFG, p. 37, L. 28-29).

Power

As in the previous focus group interview, the donor coordinators also had mixed views about their perceived *power.* Like a recipient coordinator focus group participant who said she *'had power but it was power in inverted commas',* one donor coordinator stated that she had *power* but it was limited. There is some contention around this issue for a number of coordinators:

> ... we do have power but our power is ... limited by how much they want to give us [medical practitioners] and how much they want to listen to us ... some people will give us enormous power to make decisions and others will want that power for themselves ... (DFG, p. 39, L. 12-16).

> ... most donor coordinators are fairly dynamic ... strong willed people ... and if there is a way to muscle in on a discussion they will do it (DFG, p. 36, L. 3-5).

Professional isolation

Professional isolation is a code that was shared by both groups of coordinators in the study. It is interesting to note that some coordinators perceived their practice as autonomous whilst others felt they were *professionally isolated.* There appeared to be a sense of *autonomy* and/or *professional isolation* for coordinators depending on the situation being discussed. It is clear that there is some overlap between these two codes and in some instances examples could

have been allocated to either group. The other interesting point to note is that sometimes coordinators felt *professionally isolated* even though they were part of a team they got on well with:

> ... even though I got on extremely well with my colleagues I felt like I really couldn't ... you know complain about that [doing a second donor with out having had sleep] or ... ask somebody else to do it because there was an expectation an ... ever increasing expectation I felt, that you ... just did it and that you just gave up increasing amounts of your own time to do things (DFG, p. 26, L. 24-29).

Recipient outcomes

There was only one comment that related directly to *recipient outcomes* in the donor coordinators' focus group interview. It highlights the prime reason for this coordinator's commitment to the role. This coincidently was also the only comment that emerged in the code *shared goals*. It has therefore been included in both codes because in grounded theory all concepts, ideas or codes are coded in as many places as possible (Glaser & Strauss 1967):

> ... you want to do the right thing by the recipients because I mean they're the reason you know a big part of the reason why you're doing this ... (DFG, p. 46, L. 13-15).

Relationships with donor coordinators

The donor coordinators' relationships with their colleagues were both positive and negative. The quote below highlights a negative example:

> ... I felt physically sick and I thought I cannot survive another twenty-four hours and do this properly and look after this family and I rang my colleague and explained the circumstance and he was most unsympathetic and he didn't wish to come in (DFG, p. 44, L. 31; p. 45, L.1-4).

Relationships with health professionals

There was a sense of ambivalence and unpredictability in some cases in regard to this code as is demonstrated in the first example. Anger was expressed in relation to the exclusionary behaviour that coordinators are sometimes exposed to by their medical colleagues. Certainly for the coordinator who gave the second description there appeared to be a total disregard for the contribution donor coordinators could make to organ donation matters. Not all encounters and relationships with other health professionals are so polarised. However, these were the examples given:

> ... nursing staff it depends ... on the day and time because you can go into one hospital and ... the nursing staff and the medical staff and ... the recipient teams are all great and the next time you turn around and ... the nurses are unhappy and theatres [theatre staff] ... [are] tearing their hair out and it...really just depends ... So it's always ... a bit difficult (DFG, p. 43, L. 15-20; L. 23).

> ... we didn't have an agency at that point so organ donation was kind of a stand alone autonomous yet not really existing process if you like or I should say structure I found it really interesting how within the ... committees that did exist ... how ... the ... donor coordinators didn't have any voting rights we really [were] almost ... there by ... invitation (DFG, p. 33, L. 22-27).

Respect

The code *respect* contains both positive and negative examples. The first indicates the *respect* and acceptance one participant has found in the work place. The second example highlights a less receptive working environment:

> ... I'm very lucky in a lot of ways that the role that I'm in has been ... accepted and very much respected in the area that I work ... locally (DFG, p. 16, L. 15-17).

> ... I've been shocked at the ... lack of respect, they ... admire what we do but they don't respect that we want to make it a career ... (DFG, p. 39, L. 7-9).

Responsibility

The extracts from the focus group verbatim transcripts indicate the high level of *responsibility* that is part of the donor coordinator and recipient coordinator roles. There is reference to the code *autonomy* indicating that with *autonomy* there is *responsibility* which is aptly described in the second example. The coordinator indicates that *autonomy* in the role means there is considerable *responsibility* and with that *responsibility* there is also accountability:

> ... you had to make very quick ... decisions on ... thinking on your feet all the time. It was a huge amount of responsibility in a lot of ways ... and it was just amazing how after a while that started to sit quite comfortably and you really enjoyed that part of it. Really you know enjoyed being able to tackle those challenges ... (DFG, p. 6, L. 1-6).

> ... the constant on call and the difficulty in separating personal from professional; the fact that you are dealing with death/dying/intense emotion/fear 'superstition' every day; the fact that autonomy also means that the 'buck stops' with you and you are therefore frequently in the firing line (DFG, p. 1a).

Seeing the process through

Seeing the process through appeared to be extremely important to some of the donor coordinators and is reflected below. The sense of completion and

connection with the donor family is evident in her words. The next example is a more global picture of what it means to coordinators to follow through and complete what they have started. The content of this code, however, is in direct conflict with much of what is expressed in the *occupational health and safety* code. It is not possible for one person to coordinate the organ donation process from beginning to end and not violate the principles of a safe working environment. Organ donations take an extended period of time to organise and coordinators who *see the process through* are usually working for twenty-four hours or more without sleep or adequate breaks. This is a significant dilemma for some in the profession:

> I think that was one of the best things about it, you actually could get things done you could see the process through from beginning to end, you had a sense of closure, you could feel good about the fact that you had seen that family through that and that they had been able to stay in contact with you and ... you knew all the organs went to the right places and you knew the hospital staff ... felt good about it ... (DFG, p. 12, L. 8-14).

> The rewards come from the close/intense relationships formed with donor families and colleagues; the sense of completion associated with seeing a job through, the autonomy of the role, which allows you to develop many different skills (DFG, p. 1a & 1b).

Shared goals

There was only one example of *shared goals* in the donor coordinator focus group interview. This example also relates to the code *recipient outcomes*:

> ... you want to do the right thing by the recipients because I mean they're the ... reason you know a big part of the reason why you're doing this ... (DFG, p. 46, L. 13-15).

Strong personalities

There was one reference to *personalities* in the donor coordinator focus group interview and it alluded to *personalities* sometimes not being compatible. Coordinators are often the people mediating between other health professionals who sometimes have *personality* clashes:

> ... you're dealing with so many different people and sometimes personalities just don't mix and ... I suppose that part of the job is ... trying to calm the waters ... (DFG, p. 43, L. 20-23).

Support people

The codes *support people* and *teamwork* are closely aligned. However, at this stage of analysis they were not combined, as there appeared to be subtle

differences in the two codes as discussed previously. Examples of this code include:

> ... from a local level the health professionals are supportive ... (DFG, p. 16, L. 21-22).

> ... I have great support ... on the statewide level but I am disappointed ... by the attitude at the local level of health care professionals ... (DFG, p. 19, L. 2-4).

Teamwork

Donor coordinators also value the *teamwork* and sense of accomplishment that is fundamental to the successful coordination and completion of the organ donation and transplantation process. However, as indicated in the first example there are certain conditions placed on *teamwork* and when it comes to assisting with an additional donor it would seem that *teamwork* is not seen as a priority. There appears to be an unwritten rule that one is expected to be a 'superwoman' or 'superman' in relation to completing the organ retrieval process if the coordinator happens to be the one on call:

> ... one of the best things about the job is that it was this incredibly cohesive team and ... you knew no matter what time of day or night it was you could phone your colleagues for back up, which might sound like I'm contradicting myself a little bit when I said there was an expectation that ... if there were two donors in the hospital you'd do them both, there may have been that expectation ... but at the same time there was never any problem with calling your colleagues for advice ... (DFG, p. 4, L. 18-26).

> ... there was that kind of companionship and buddy-ness ... if I didn't know something then someone else would help me out (DFG, p. 4, L. 30-31; p. 5, L. 1).

Uniqueness

Unlike their recipient coordinator colleagues the issue of *uniqueness* did not feature prominently in the donor coordinator focus group interview. In the context of this interview the following two statements were made; the first alludes to transplant coordination as an experience that many are never part of. The second example relates to the fact that organ donation as an entity is unique in that it relies on the public charity:

> ... you've been ... a part in something very special that not many people can actually say that they've ever been a part of ... (DFG, p. 15, L. 15-17).

> ... organ donation ... is in such a unique position because it's the only government department ... that depends ... on the communities' sense of

> charity, I don't think that is recognised ... (DFG, p. 28, L. 15-18; L. 20-21).

Use of skills

Participants agreed that the role enabled them to use their current *skills* and to learn and develop new *skills.* As the examples indicate this makes the role rewarding and gives them highly beneficial career opportunities. This code is also linked to autonomy as is identified in the first example:

> ... the autonomy is a ... wonderful thing about this job. I think also it does provide you with the opportunity to use all your skills (DFG, p. 4, L. 1-3).

> It's given me opportunities that I think a lot of people would never come across and I find that to be really rewarding and something I can certainly carry with me through the rest of my life in a career (DFG, p. 4, L. 17-20).

Variety of people

Donor coordinators spoke positively about the *variety of people* they meet in their practice. There was also some discussion about the fact that coordinators, particularly in the past have come from various backgrounds ranging from dental therapists to flight attendants indicating that within the specialty itself there was a broad range of *skills* and backgrounds:

> I'd have to say it's very rewarding meeting the people that you do both within the health care system and the actual ... donor families ... (DFG, p. 3, L. 7-9).

> ... transplant coordinators ... certainly came in with varied backgrounds ... (DFG, p. 4, L. 28-29).

Workload

As with recipient coordinators, donor coordinators too, at times, felt overwhelmed by the expectations and the physical demands of their role. As society becomes more litigious in nature so does the need for additional legal safeguards within the coordinators' practice. This consequently increases the *workload* for those involved in organ donation. There was also a perception that there are many 'fingers in the pie' creating the need for careful negotiation and an ability to consider the wishes of many. Finally, there was a sense that the organ donation process is becoming more difficult. As one coordinator states, when you have a small group of very over-worked people it is hard to address many of the issues:

> ... There's not the appreciation of how hard the job can be and is becoming. And it's becoming increasingly hard and it's about to become increasingly harder and I think in some ... instances we've ... entrenching

> ourselves in paper work to the point where ... [we will] not have a donor rate ... because there are so many legal considerations and so many people sticking their fingers into the pie now that it's getting harder and harder to actually run through the process (DFG, p. 22, L. 13-21).
>
> ... when you've got a small group of very over-worked people ... who ... expect an awful lot from themselves and everyone's off doing research and you know doing twenty four hour shifts and all this sort of thing it's very hard to pin people down and ... have meaningful discussions about things like [pause] legal safe guards and ... paper work type stuff (DFG, p. 24, L. 8-16).

Comparison of codes and preliminary categories from the focus groups

Comparing the codes and preliminary categories that emerged from the donor coordinator focus group interview data with those that emerged from the previous focus group data resulted in further development of the five preliminary categories. In addition one new preliminary category emerged, labelled POOR REGARD FOR COORDINATORS AND THEIR ROLE as shown in Figure 5.9.

The information in bold print indicates that the preliminary categories, subcategories or codes relates to data from the donor coordinator focus group interview only. The non-bold print indicates that the preliminary categories, subcategories or codes are common to both the donor coordinator and recipient coordinator focus group interviews.

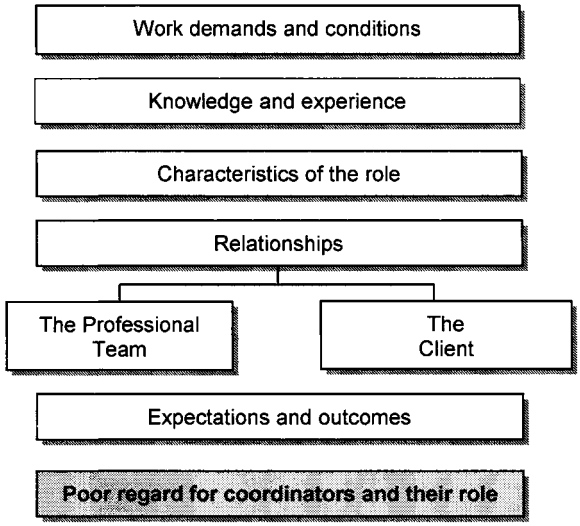

Figure 5.9: An overview of preliminary categories following analysis of the focus group interview data

WORK DEMANDS AND CONDITIONS

The preliminary category WORK CONDITIONS emerged from the open coding of the recipient coordinator focus group interview data. During open coding of the donor coordinator group data additional examples were added to the pre-existing codes. Four new codes emerging from the data were also included in this category. These were *inequity in funding*, *leaving the job, organ donation as a business* and *political and bureaucratic issues* as shown in Figure 5.10. The additional codes resulted in the name of the preliminary category being changed to WORK DEMANDS AND CONDITIONS to more accurately reflect its content. Examples of the four new codes included:

> ... the cost of fifty dollars per family is seen as ... excessive where as the reality ... certainly in this state ... we're talking about ... in excess per thousand for a donor by way of the material body that's not seen as excessive and I just find that really difficult to ... to put those figures together (DFG, p. 29, L. 23-29).

> I don't think there's time for regrets, I think it's a job that when you do it, everyone does it to their full capacity and when you leave you leave hopefully with a lot of fulfilment that you've done your best and you've tried really hard and you've ... won many lost a few ... and that's life ... as far as regrets go ... I don't think it's the type of job that you regret leaving. I think it's the type of job that takes as much as it gives and at the end you call it quits (DFG, p. 15, L. 11-20).

> ... now we're a business that has to justify itself so if the organ donation rate drops then you get a ministerial ... saying we've noticed the organ donation rate has dropped ... tell the people ... in this hospital they better pick up their act. And I find that quite hideous and I think the public would find it quite hideous (DFG, p. 21, L. 24-29).

> ... the politics is rife ... (DFG, p. 21, L. 9-10).

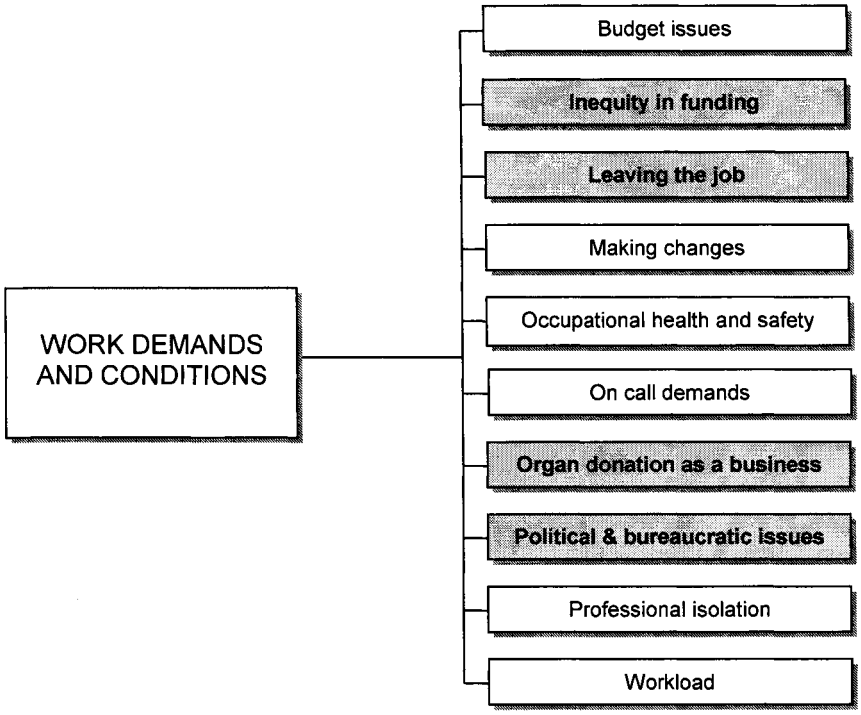

Figure 5.10: Preliminary category - Work demands and conditions

KNOWLEDGE AND EXPERIENCE

This preliminary category emerged following the open coding of the recipient coordinator focus group interview transcript. During open coding of the donor coordinator interview transcript, data was added to some of the existing codes in this preliminary category as shown in Figure 5.11. This resulted in further development of the codes and added to the density of the information contained within them and the preliminary category. No additional codes emerged from the data analysis of the second focus group interview.

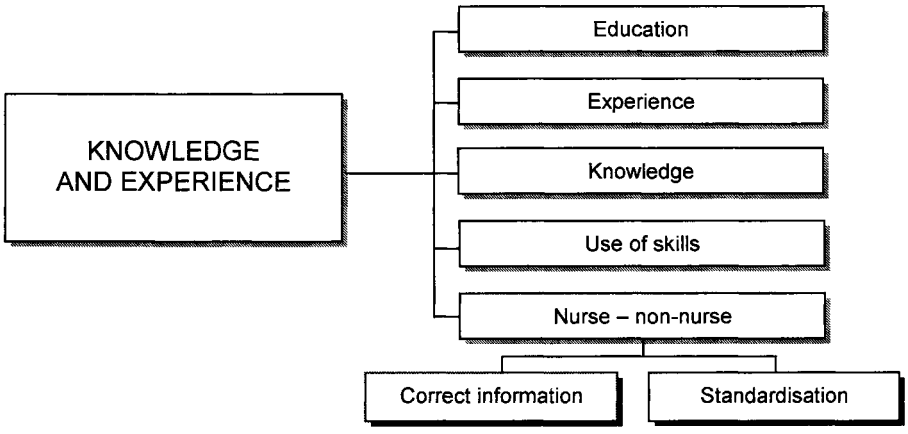

Figure 5.11: Preliminary category - Knowledge and experience

CHARACTERISTICS OF THE ROLE

The preliminary category CHARACTERISTICS OF THE ROLE emerged from the first focus group interview and several of the pre-existing codes it contained were expanded following open coding of the second focus group data. Two additional codes – *challenges* and *intimacy of the job* – were included in this preliminary category. The additional codes are shown in Figure 5.12. Below are examples from the new codes:

> ... I've only been in the job for twelve months and I've basically been able to work it out for myself which I found is really good. Challenging once again is another high point ... (DFG, p. 7, L. 7-10).
>
> ... intimacy is certainly ... [a] real attraction to the job ... (DFG, p. 15, L. 1-2).

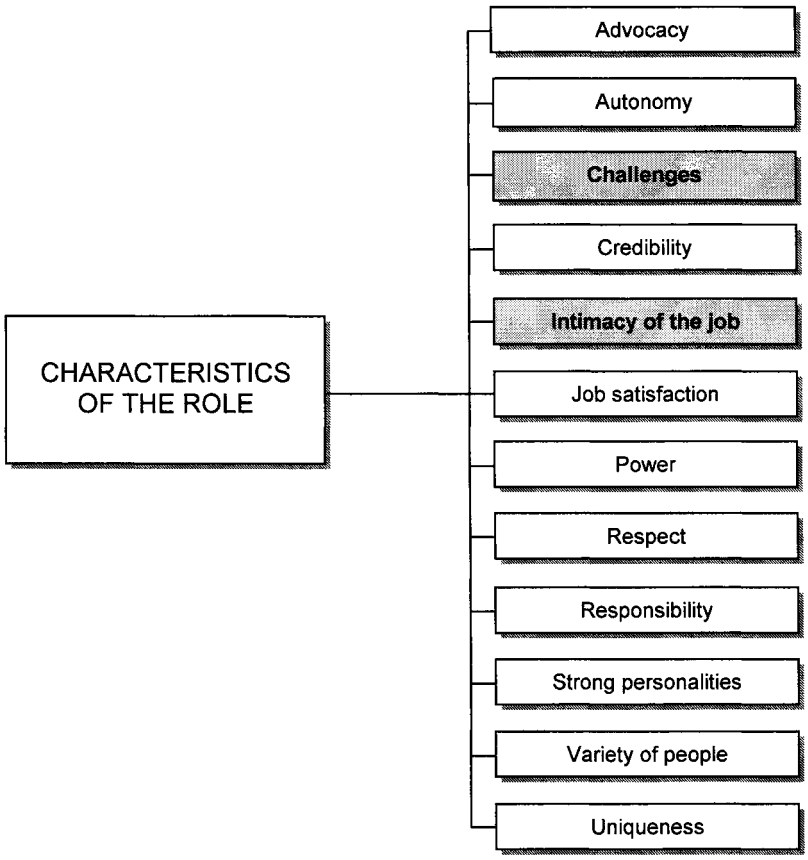

Figure 5.12: Preliminary category - Characteristics of the role

RELATIONSHIPS

This preliminary category had two subcategories. Many of their codes emerged from the recipient focus group interview and further information was added to a number of the pre-existing codes following analysis of the donor coordinator

focus group data. The code *difficulties with doctors* was also changed to *difficulties with doctors and nurses* as it became clear from the data of the second interview that there were also difficulties with nursing staff on occasions. In the subcategory *THE PROFESSIONAL TEAM* five new codes were added. These were *competition, consensus, control issues, non-supportive colleagues* and *relationships with recipient coordinators* as shown in Figure 5.13. Examples from the extra codes that emerged include:

> This results in a sense of competition between colleagues/states rather than a sense of cooperation and mutual support (DFG, p. 1b).
>
> ... the incredible difficulty of getting ... national consensus ... (DFG, p. 22, L. 29).
>
> I'm someone who likes to have some control over their life that likes to be able to plan and being on call all the time takes that away from you ... (DFG, p. 25, L. 26-28).
>
> ... rather than call my colleague at times within my own state I would call another state ... And that for me was easier than going through the rigmarole of dealing with my colleague (DFG, p. 44, L. 10-11; 15-17].
>
> ... I've been fortunate to have been both [a recipient & donor coordinator] so I've even allocated to myself (DFG, p.47, L.10-11).

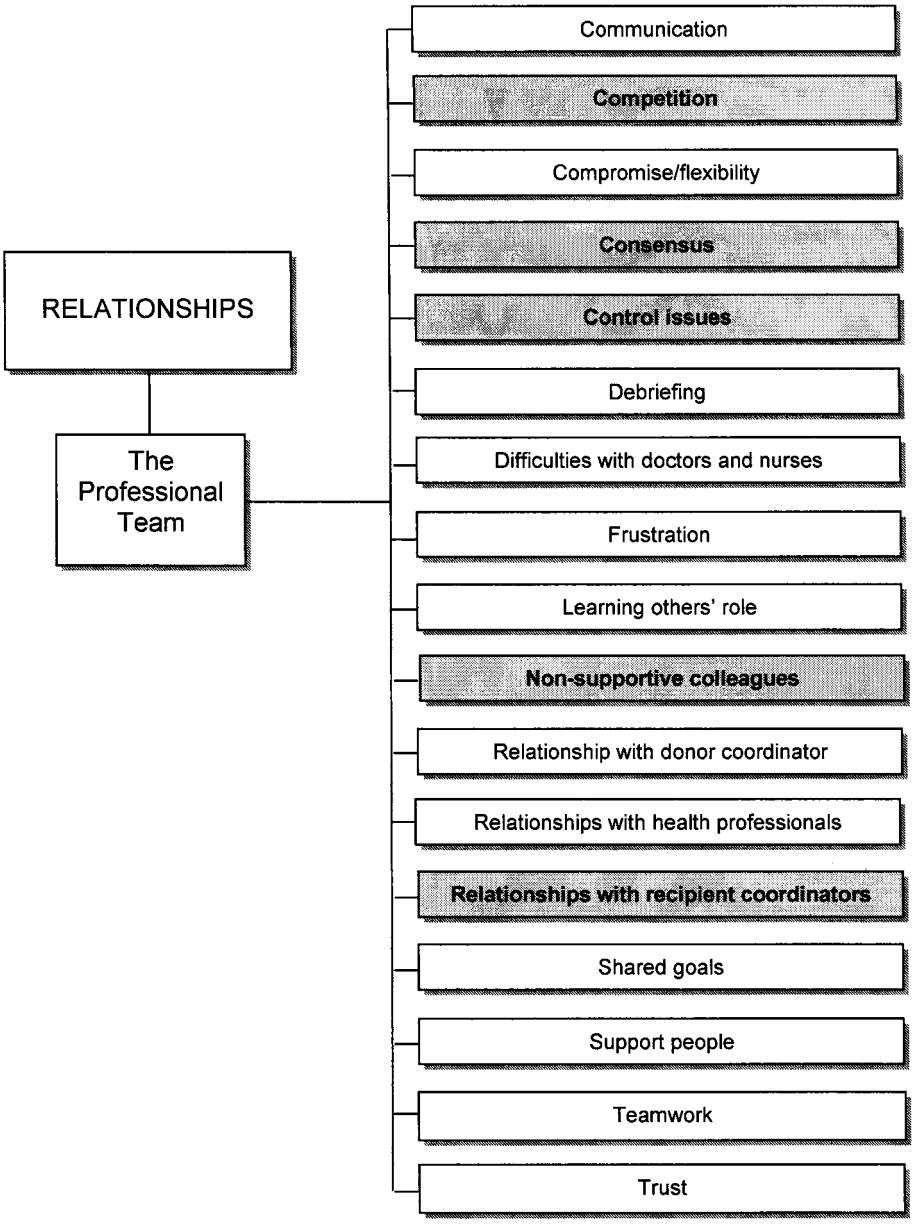

Figure 5.13: Preliminary category - Relationships and the subcategory - the professional team

In the subcategory *THE CLIENT* two further codes emerged from the data. These were *care of donor families* and *relationships with donor families* as shown in Figure 5.14. These codes shared no common data with the recipient coordinator participants. This is not surprising as their client groups are different with recipient coordinators caring for potential and actual transplant recipients and their families and donor coordinators caring for donor families. Below are two examples that emerged in the additional codes:

> Empowering by role modelling and information giving to both health professionals and donor families (DFG, p. 10).
>
> ... donor families are extraordinary people (DFG, p. 3).

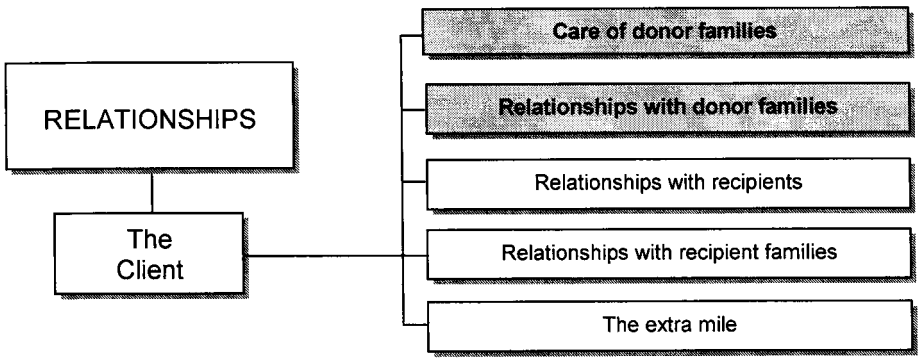

Figure 5.14: Preliminary category - Relationships and subcategory - the client

EXPECTATIONS AND OUTCOMES

This preliminary category was represented in the data that emerged from the first coordinator focus group interview. Following open coding of the second focus group data two new codes, *donor family – recipient contact* and *donor family outcomes* were added to the preliminary category EXPECTATIONS AND OUTCOMES as shown in Figure 5.15. As was the case in the other preliminary categories more information emerged for the pre-existing codes. Examples of the new codes are shown below. The first reflects a donor coordinator's wish to be consistent with donor families. The second highlights one of the dilemmas for donor coordinators in relation to the ongoing debate about whether donor families and recipients should meet:

> ... it [is] difficult to be consistent with families sometimes ... (DFG, p.24, L.3-4).

> The issue relating to donor families and recipients meeting everybody knows is complicated ... (DFG, p. 34, L. 13-14).

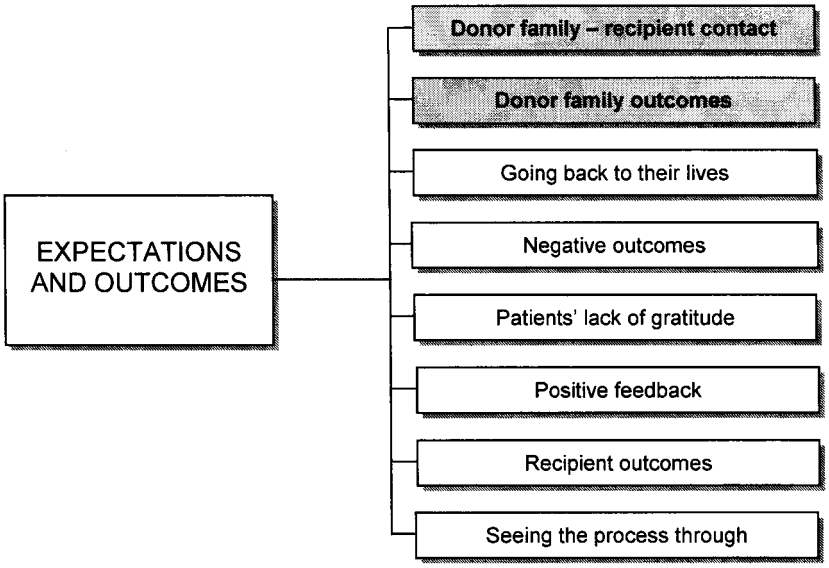

Figure 5.15: Preliminary category - Expectations and outcomes

POOR REGARD FOR COORDINATORS AND THEIR ROLE

The final preliminary category is one that emerged from the analysis of the donor coordinator focus group interview data. There are six codes: *bad behaviour, bullying, put-downs and undervalued, expendability, lack of acknowledgement, others knowing best*, and *voice not heard.* They make up this category as is shown in Figure 5.16. Each of these codes relates to coordinators and their role being undervalued and at times held in poor regard. Listed are some relevant examples offered by the donor coordinators. The first two demonstrate a lack of respect toward coordinators and the contribution they make to the field. The third clearly articulates that medical officers can impact negatively on the organ donation process and obstruct coordinators in terms of their practice:

> Now I know that the length of a transplant coordinator's working life [in the role] is short but I think sometimes it is intentionally made short because of the little comments, 'Oh they'll only last a short time before you can stick someone else in there and you know they'll wise up and in two years and then you can give them a hard time and perhaps they might move to another pasture' (DFG, p. 38, L. 20-26).

> ... the attitude is that transplant coordination is something that mainly women do ... (DFG, p. 38, L. 26-27).

> ... there are ... numerous other examples where people [doctors] behaved badly where they allowed their own ego ... to dictate the terms of events ... with really, I have to say, little or no regard towards other individuals, it was an ego trip for them ... they weren't concerned about, if you like, the donor family, they weren't even concerned about the possibility ... of supporting the donation process (DFG, p. 33, L. 7-9; L. 13-17).

The next example is one from the code expendability and demonstrates a distinct disregard for the health and wellbeing of the coordinator concerned:

> ... when I came in and said one day I'm finding it really hard he said, 'Well I was actually ... waiting for you to break and then I was going to do something but you needed to break or no one would listen to me' (DFG, p. 37, L. 30-31; p. 38, L. 1-2).

Some of the coordinators appear to be very angry and despondent regarding their inability to be heard in some areas of practice:

> ... it's an extremely negative part of the role and is enmeshed now into the politics ... but there's definitely a strong feeling of not being able to provide input ... (DFG, p. 37, L. 4-5; L. 7-8).

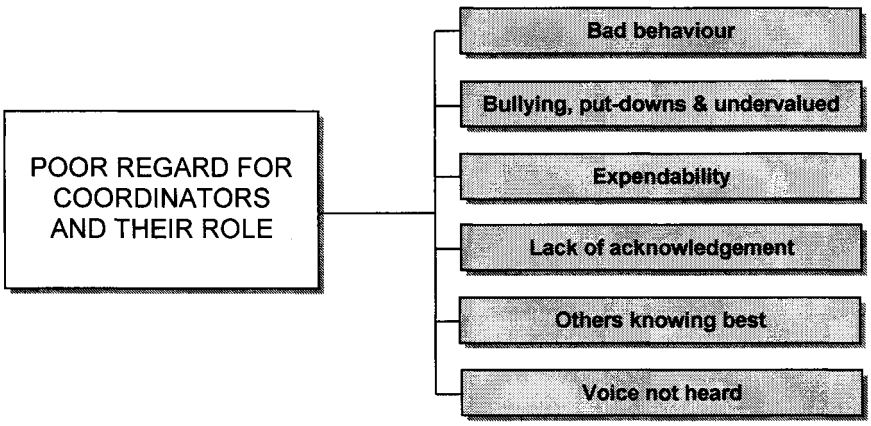

Figure 5.16: Preliminary category - Poor regard for coordinators and their role

Figure 5.17 provides an overview of the codes, subcategories and preliminary categories that emerged from the analysis of the focus group interviews.

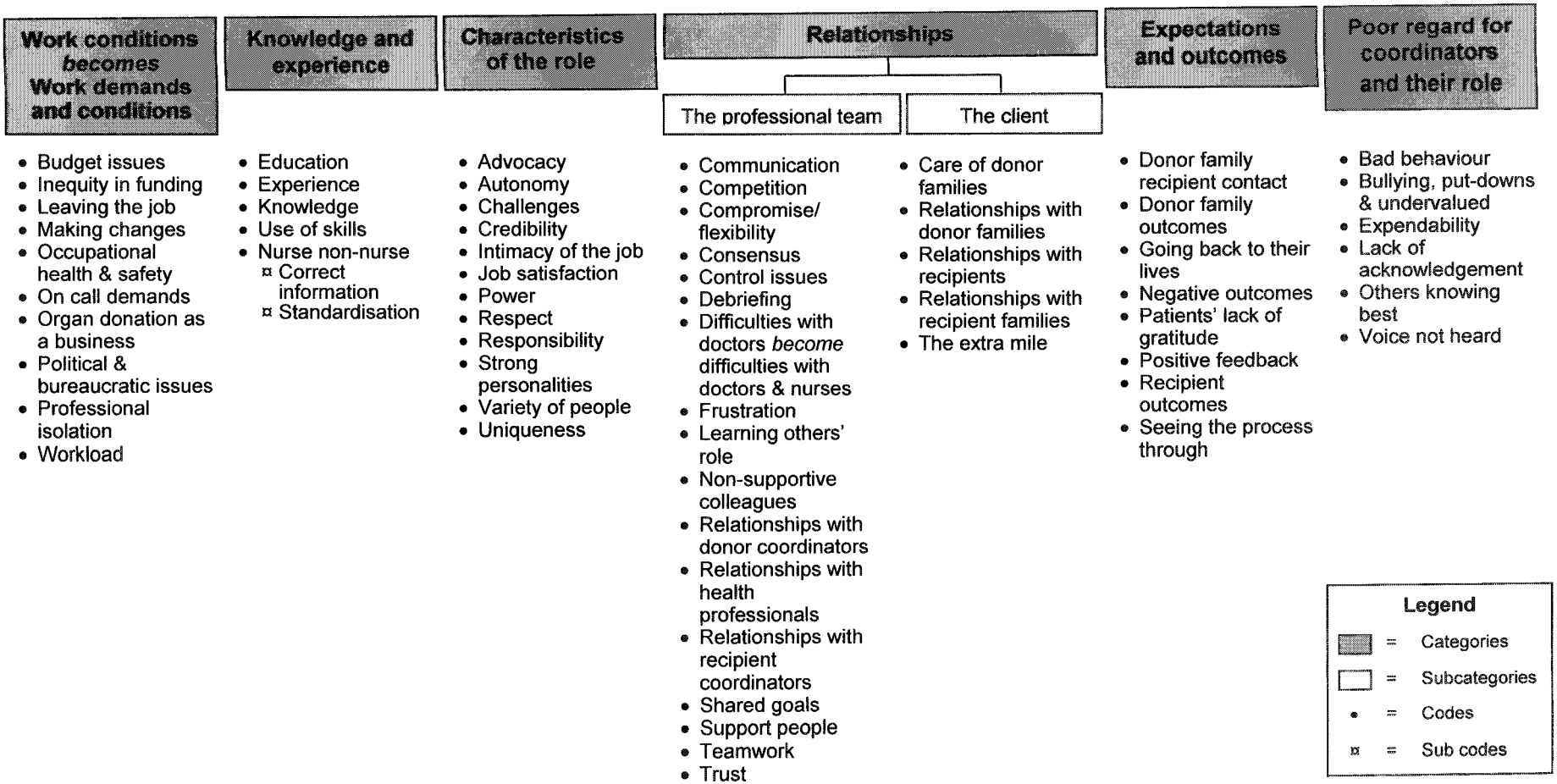

Figure 5.17: An overview of the codes, sub categories and preliminary categories that emerged following the completion of the analysis of the focus group interviews

Summary

This chapter provided a detailed description of how open coding was used to constantly compare and analyse data from the donor and recipient coordinator focus group interviews. It explored the codes, subcategories and preliminary categories that emerged from the interview data. Six preliminary categories were identified.

1. WORK DEMANDS AND CONDITIONS
2. KNOWLEDGE AND EXPERIENCE
3. CHARACTERISTICS OF THE ROLE
4. RELATIONSHIPS
5. EXPECTATIONS AND OUTCOMES
6. POOR REGARD FOR COORDINATORS AND THEIR ROLE.

At this stage it would appear that the preliminary category RELATIONSHIPS might be the core category but it is too early in the analysis to confirm this.

Chapter Six and the chapters following expand on the preliminary categories that were outlined here. This will be achieved by analysing quantitative and qualitative data collected through theoretical sampling. The statistical data collected in the two Delphi survey rounds through the use of a Likert scale is discussed in the next chapter. Chapter Seven discusses the selective coding of the qualitative data also collected in each of the Delphi survey questionnaire rounds. These processes will assist in confirming whether or not RELATIONSHIPS is indeed the core category. Finally, theoretical sampling and selective coding will enable the properties of the preliminary categories and categories and the links between them and the core category to be identified.