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**Altruistic kidney donation: a discourse analysis, and the client's use
of the body for unconscious communication.**

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Portfolio submitted in fulfillment of DPsych Counselling Psychology,
Department of Psychology, City University London.

February, 2012

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Declaration

I grant powers of discretion to the University Librarian to allow the thesis to be copied in whole or in part without further reference to the author. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

Section A: Preface to the portfolio

This portfolio is comprised of three sections: two pieces of clinical work and an empirical research project. The clinical pieces are a case study, formatted as an article for submission to a journal, and a combined case study and process report. Both have been completed during my training in counselling psychology at City University and illustrate my competence and emerging approach to the discipline, providing evidence of my knowledge and skills in theory, research and practice.

Both of the clinical cases presented here took place in a primary care counselling setting. The client's use of the body in unconscious communication, and links between psyche and soma are themes that run throughout this portfolio of work. Taken together, I hope that the studies demonstrate the trajectory of my training as I have learned to practice using psychodynamic theory in a way that feels authentic to me. Through supervision I have been guided towards a contemporary relational approach to psychoanalysis that together with object relations theory, forms the theoretical basis of both pieces of work.

Coincidentally, both clients presented with ulcerative colitis, a disease that has long been of interest to psychology. One was a relatively mild case and I felt that the illness was a way for the client to experience feelings of loss towards himself. For the other client however, the severity of the disease symptoms and the drastic treatment that was being proposed by her doctors had become a source of great distress and needed to be worked with as an expression of the psychological trauma that preceded the physical disease. The symptoms seemed to me to be an embodiment of feelings that could not be tolerated, and importantly could not be spoken about. I describe the process of therapy with this client, who was mourning the suicide of her only child, and whose health was now being gravely threatened by ulcerative colitis. There were also cultural and language aspects to this work that increased its complexity. In the article, I conceptualize the client's physical disease as the embodiment of her experience of psychic disintegration in grief. I draw on Freud's theory to suggest that her illness can be thought of as an unconscious sadistic attack on herself. Tolerating her unbearable pain and not turning away from it became the work of our sessions and at first this was all the work that could be done. Through surviving this, the client's need to be believed became a central theme and drove both the transference-countertransference and the therapeutic relationships, and I struggled to apply psychodynamic theory in a

way that felt therapeutic rather than persecutory. By using supervision and psychodynamic theory to think about this conflict in terms of what it could tell me about my client's subjective experience, I was able to begin to reconcile this difficulty and more fully understand and therefore help her.

This was not the first time that I had worked with a parent who had lost a child, and each time I struggled to find a way to think about how counselling psychology could help a person going through this most unimaginably painful of experiences. That this case was one of the last that I undertook during my training seemed somehow fitting, as I had begun my counselling psychology as a bereavement counsellor. I was in my mid-thirties when I began psychology and counselling training. Working as a counsellor with loss and bereavement provided my entry into a world of other peoples' pain and it was the experience of struggling to survive that pain alongside those clients that sparked the desire to train further and understand the therapeutic process better. An interest in the way that people face the processes around death and dying was one of the reasons that I was drawn to the subject of altruistic organ donation for my research.

The second piece in this portfolio is a combined case study and process report for a client who came to counselling at the suggestion of his doctor, and because he wanted to understand frequent feelings of anger and irritation. From the beginning, he wanted to know what the effect of his mother leaving him when he was three years old might have been. In the study, I suggest a formulation that hypothesizes that this client experienced a chronic failure of empathy in his early development, with the result that he is acutely sensitive to experiencing empathic failure as an adult. The shame and guilt that he experienced growing up made him feel intensely self-conscious and anxious when confronted with the idea of being held in mind by another individual. I experienced his difficulty over a number of weeks with a growing sense of unease about my own ability to reflect his feelings in a way that I felt was sufficiently empathic. In the extract of the session I have presented, I begin to respond to these therapeutic relationship difficulties, becoming more aware of moments in which the relationship faltered, when I failed to reflect to the client my experience of him in that moment. This process report is therefore a piece of critical reflection and learning on the here-and-now processes of therapy. Through writing it, I was able to improve my practice and understand more fully how fundamentally important here-and-now interpretations are to the therapeutic process.

The final section is a piece of in-depth qualitative research, using discourse analysis and a psychosocial research paradigm that to my knowledge has not been applied in a counselling psychology context before. This method attempts to bring together, in an occasionally uneasy partnership, social constructionist and psychoanalytic approaches to research. Although both paradigms have language at their heart, they make very different assumptions about what can be known about the subjective experience of others. However, it was important to me to find an epistemological approach that was not only capable of answering the research questions, but one that was also compatible with what I was aiming to do in my counselling psychology practice. Reconciling the social constructionist method of discourse analysis with the psychodynamic goal of understanding and making meaning from the unconscious experience of another individual has been a fascinating and challenging process.

The subject matter for the research project - altruistic kidney donation - arose unexpectedly as the result of a placement in the renal department of a large teaching hospital. My role there was to deliver counselling psychology interventions to kidney patients. Some were finding their diagnosis difficult, or approaching the need for dialysis, others were struggling with being on dialysis, while some were facing transplant, or were post-transplant. One of the roles of the consultant psychologist who was my supervisor was to assess individuals who were spontaneously offering to donate one of their kidneys to a stranger. My response on learning of the existence of this small group of people was one of curiosity; I wanted to understand what motivated somebody to do what seemed to me at the time to be an extraordinary thing. But the idea of altruistic donation also provoked considerable anxiety in me from that first instant and I was interested in exploring what this anxiety might be about, and wondered to what extent it might exist for other people and what effect, if any, this might have on practice.

Initially, I thought about exploring the relationship between psychological “knowledge” and power in relation to altruistic donation and the way in which psychological and medical assessments might be used to subjectify donors who come forward wanting to donate a kidney to a stranger. This pointed towards a Foucauldian discourse analysis, but through piloting the semi-structured interview, I became interested in the extra-discursive aspects of altruistic donation, the particularly embodied, very personal nature of the communication that was taking

place both in the donation itself and in the research interview, and the extent to which, if at all, this embodied experience might be accessible for interpretation.

In line with my counselling psychology practice, psychodynamic theory was used as a way to think about those aspects of the participants' experiences for which they had no words and perhaps were choosing instead to use their bodies to communicate, and led to the possibility of exploring possible unconscious aspects of this type of organ donation. I was also concerned about the implications for my counselling practice if I chose a purely social constructionist method. At the time, I was beginning to focus on a psychodynamic model of counselling, learning to use my relationship with the client to make interpretations about their subjective experience. I felt strongly that if this relational approach to interpretation was guiding my practice, it made no sense to use a research epistemology that argued against what I felt to be the most useful way of doing therapy.

The methodology I chose therefore draws on a psychosocial research paradigm. This posits that social and psychic accounts be treated as equally privileged entities, with the goal of critically exploring the complex interaction of social and intra-psychic factors that occurs when an individual engages with the discursive tools available to them. My method integrates Foucauldian and discursive approaches to discourse analysis with positioning theory and psychoanalytic thinking. It required an approach to reflexivity in interpretation that developed in parallel with my practice. The reflexive nature of counselling psychology, and the use I make of my self, therefore provides a link between interpretation in research and interpretation in therapeutic practice. In both, I am aiming for a potentially useful, constructivist understanding of an individual's subjectivity that aids meaning making, yet is non-pathologising. It has been important to be able to justify an interpretive process that can be applied in both research and practice, with the difference being in the intention with which the interpretation is made.

The results of a discourse analysis generated three major themes: other-oriented, rational and self-oriented discursive strategies. Participants used these discursive strategies to position themselves as concerned only with the needs of the recipient, to resist questioning and criticism in the interview, and to demonstrate the rationality of donating. Most participants rejected the possibility that some of their own needs might be met through donating, so discourses of the self were used rarely, in line with the prevailing social understanding of "altruistic" donation.

In contrast, medical, engineering and mechanical discourses were extensively drawn on, and I have suggested that one important function of these for participants is to separate mind and body, thereby defending against difficult feelings about the self, death and dying. From the theoretical perspective of a dynamic unconscious, participants experienced their desire to become altruistic donors as compelling. I conclude that the use of the term “altruistic” to describe living non-directed organ donation constrains available discourses and therefore practice, and allows for the donors to be constructed only either as saints or as “mad”, severely limiting what can be said, felt, thought and done by donors, clinicians and society.

I believe that this study demonstrates the compatibility and usefulness of psychosocial methodology applied at the interface between the individual, the clinic and society. Both social constructionism and psychodynamic theory do not easily fall within the humanistic and phenomenological traditions of counselling psychology but I am drawn to the discursive as a way to take account of the inescapably social aspects of individual experience. I feel that this ought to form an integral aspect of what counselling psychology as a discipline strives to do, yet in addition to these social influences, I also want to attend to the internal aspects of a person’s experience and so draw on a critical-realist approach to social constructionism. In counselling practice, I have also found that I can most usefully understand and therefore help clients by integrating theories about the discursive and the unconscious. Part of the attraction of this way of practicing for me is that it does not make change a goal in itself, rather, change is conceptualized as coming about as the result of insight and understanding.

My thesis is that interpretation in counselling psychology research should not end with language, and my goal in this portfolio has been to explore the extent to which it is possible to usefully interpret not only the discursive, but also the extra-discursive aspects of inter-subjective experience. Furthermore, I argue that it is important to recognize that both (the discursive and extra-discursive) are co-constructed in therapeutic practice and research, and experience, whether conscious or unconscious, can be communicated using the body and action. Psychodynamic thinking, with its focus on the unconscious, offers one way to theorise this communication. There may also be other means of doing this. I believe that the client who brings their illness symptoms to counselling, and the altruistic kidney donors who offer a part of themselves to a stranger are

communicating something important about their subjective experience. Attending to what is being said not just in words, but also through the body, therefore adds an extra dimension to relational thinking and counselling psychology practice.

I hope that this portfolio demonstrates my ongoing work to become a reflexive practitioner who is able to give clients an experience of being understood, and so feel more able to bear previously intolerable feelings. I have chosen to work using a psychodynamic model and to extend this to my research because this approach best reflects of my personal understanding of the way in which we are able to know another person's subjectivity. It seems to me that change is unlikely to occur unless we first try to understand another's experience of being in the world, and that through understanding, we increase our ability to bear the inevitably painful aspects of the human condition. Although as counselling psychologists we strive to do this to the best of our ability, it will nevertheless always be an imperfect understanding. Learning to be in as genuine as possible a relationship to this struggle has shaped my personal journey to become a counselling psychologist, and will continue to be at the heart of my approach.

Section B: CLINICAL ARTICLE

(Formatted for submission to Psychodynamic Practice according to the journal's Instructions for Authors – see Appendix B1)

“Working with the unworkable – a case of maternal mourning and Ulcerative colitis”

B.1. Abstract

In this paper I describe a time-limited piece of work with a mother whose child committed suicide. The client went on to develop serious ulcerative colitis that I have conceptualised as the embodiment of her experience of disintegration in grief. Using Freud's theory of identification with the lost object, I suggest that her illness represented an unconscious sadistic attack on herself and the identified-with lost object. Unconscious phantasies of harming the lost loved object resulted in guilt and resistance to making a link between her disease and her grief. I experienced this as a projective identification that made it difficult for me to work in the transference. Her failure to make herself better both from her disease and from mourning her son made her continue to feel like a victim. Being believed became a central theme of the work, reflecting the trauma she had experienced and her resulting belief that she would not be understood, annihilating her ability to make meaning.

Keywords: Maternal mourning; identification with the lost object; ulcerative colitis; relational model; trauma; suicide.

B.2. Introduction

This paper describes one of the most emotionally demanding and complex pieces of therapeutic work undertaken during my Counselling Psychology training. It took place in my final year of training and consisted of just twelve sessions over six months.

Brice (1991) suggests that maternal mourning is essentially paradoxical – the mother wishes to recover from her child's death but by completing the work of mourning she faces losing connection with her child entirely. Learning to work with my client's interminable pain ultimately provided me with one of the most important pieces of learning of my training. This paper is about the struggle to find a way to stay in the room together and think about how it felt to mourn for my client's lost child and her own lost life. Brice (1991) describes the utter psychic devastation of maternal mourning: "...a bereaved mother experiences her child's death as an attack she can only conflictedly fight; as the death of her world, as the destruction of her past, present, and future, and as an identity and reality crisis" (p17).

For this case, I have drawn on a relational psychoanalytic model. Layton (2008) describes how this model emphasises a two-person psychology and subjectivity is viewed as constructed both from unconscious relating to internal objects in phantasy and the experience of actual external relating with other people. Hoffman (1983) argues that the subjectivity the client brings to the therapeutic relationship is endlessly flexible, with each client interpreting and fitting their own perception of the therapist's countertransference according to the needs of the moment and through their own perceptual lens. This includes the client's perception of the therapist's ability to receive and be attuned to their experience (Stolorow & Atwood, 1992). The client's experience of the therapist is viewed therefore as plausible rather than as a distortion, and the therapeutic relationship is seen as co-constructed (Greenberg & Mitchell, 1983). In this model resistance is understood as what happens at the boundary between what can be made conscious and what has to remain unconscious in the therapeutic relationship, and is a response to the client's perception of being received accurately by the therapist or not (Stolorow & Atwood, 1992).

B.3. The case

The setting was an NHS Primary Care Trust Counselling and Psychotherapy service. The client, Mariam¹, had a diagnosis of acute ulcerative colitis for which drug treatment had been unsuccessful and for which the only remaining treatment option was surgery to remove her colon. Mariam had been referred to the counselling service by a hospital Psychiatrist because of the difficulty she was having in deciding whether to undergo the surgery her doctors were advising. The Psychiatrist had assessed Mariam and decided that she was not suitable for intensive psychotherapy with him because she was pre-occupied with her physical illness and would instead benefit from a more “supportive arrangement”. This was Mariam’s third psychotherapy referral in under than a year; she had previously had nine sessions with another Psychiatrist training in psychotherapy. I imagined that she might be feeling angry, rejected and bewildered at having to begin again with yet another counsellor. I also felt a twinge of narcissistic irritation as though what I offered was somehow less meaningful than the Psychiatrist’s.

When I collected Mariam from the waiting room for our first session I met a dark-haired woman with a gravely beautiful but tired-looking face. She wore jeans and minimal jewellery and make-up. She spoke softly in accented English that was mostly fluent although occasionally she would search for a word. She took her seat in the therapy room, and after I had introduced myself, she told me how difficult it was for her to attend appointments because of the severity of her ulcerative colitis. She seemed anxious that I understand this.

Her disease caused intensely painful and distressing symptoms. She took six different kinds of medication in an unsuccessful attempt to reduce the ulceration in her colon. She told me how she bled internally almost continuously, and so was prone to infection, anaemia and exhaustion. She described how ashamed she felt about her symptoms, which left her feeling dirty and depressed about her appearance. She could not bear the thought of the operation to remove her colon, even though this would take away her symptoms completely, because it would leave her with a stoma, an opening from her small intestine to the outside of her abdomen, and a bag to collect waste. By the time she came to see me, the operation was on indefinite hold. She said that could not imagine being naked in front of her husband with such a thing. She cried fearful tears like a child as she

¹ All names and biographical/personal identifying details have been changed throughout in order to preserve confidentiality.

described these feelings. I wondered then whether her illness performed a function of some sort and therefore could not be let go of.

Her colitis had begun suddenly, six years previously, when Mariam had been to her country intending to visit the grave of her son, Saeed. Mariam had not at that time, or any time since, been able to visit her only child's grave. She said that she had been afraid that she would "lose control". My sense as she described this was of a fear of total disintegration and her symptoms were a physical representation of the loss of control of what was inside her. Mariam came to the UK shortly after Saeed's death, where she had married again, an older man of the same nationality.

Saeed had committed suicide twelve years before by hanging himself. He was twelve years old. Mariam had divorced his father when Saeed was eight because of extreme physical and verbal abuse in the marriage. She described her ex-husband as violent and extremely paranoid. He did not believe that Saeed was his son and would accuse Mariam of infidelity, telling her she was a toilet for everybody to come to. She thought that he might kill her and worried about what would happen to Saeed if she died.

In the two years between their separation and divorce, Saeed lived with Mariam and she described this time as the happiest of her life. She adored having her child with her but felt that he missed his father. After the divorce, the law required Saeed to live with his father while Mariam stayed at her parents' home in another city. She visited Saeed as often as she could at weekends and for holidays. In that first session she said that she wished that Saeed's father had killed him, rather than that he had killed himself, because then she would have someone to blame.

As Mariam told me of Saeed's suicide, I experienced a sense of her total internal destruction and as she cried, I couldn't stop myself from crying too. I felt momentary panic as this was happening, concerned that she might experience me as unable to contain her grief. I tried to reflect on whether my tears were a genuine response to Mariam, or whether they reflected my imagined grief about what it would feel like for one of my own children to die in this way. I was particularly troubled by the idea of a child so distressed that they would kill themselves. This aspect of it felt counter-transferential. I was dimly aware that I must not use this process of reflection as an excuse to unconsciously turn inward and away from Mariam as a way to avoid her unbearable grief. The only conclusion I was able to reach at the time was that Mariam's story was so desperately sad that not to be affected by it seemed perverse.

Over time, I was able to think about Mariam's grief as belonging (mostly) to her. Having worked through this process alone and in supervision, in later sessions when tears came to my eyes I was less afraid to show her how her story affected me. Mariam knew how difficult I found the work, and would apologise to me from time to time, yet it was not until the final minutes of the last session, as we were saying goodbye, that she asked me whether I was a mother.

Mariam told me that she was not suicidal but gave a slow smile as she told me that sometimes, when she was feeling her worst, she felt that her son had shown her "a way out". This seemed comforting for her. From the beginning then, Mariam brought to our sessions the work of endings – the ending of the life of her beloved only child, the ending of her health and hopes for the future, the many endings she had had with previous therapists, and since this was time-limited therapy, looming over us, the end of our own relationship.

Mariam said she wanted to know why her feelings of grief had not lessened in twelve years. I thought of Bion's (1959) theory of containing, in which feelings that are too powerful to be tolerated may be split off and projected into the therapist, whose job it is to keep them and change them into a form that can ultimately be safely re-introjected by the client. I offered Mariam twelve sessions, the most I was able to offer a client without further discussion with the clinical head of service.

B.4. Resisting links between physical illness and grief

Mariam described how she had feared that if she stood at Saeed's grave, she would "lose control". The image I had of her child's body in the ground felt almost unbearable at that moment. I thought about how her idea of losing control was being embodied (Brice, 1991) through the symptoms of her ulcerative colitis. Her internal bleeding was like a physical representation of the grief that was private and hidden. She vehemently rejected the operation that would relieve her of her crippling symptoms but would leave her with her grief; visible, shameful and awful.

Mariam was proud of her professional scientific background and secular beliefs. She had read widely about her illness and knew of the alleged links between ulcerative colitis and chronic psychological stress. Despite knowing this intellectually, she was resistant to it. She told me that her doctors all advised her to try to relax and to reduce stress with counselling, but in the overwhelming context of her grief this felt absurd to her. She withheld information about Saeed from her medical doctors. If they asked whether she had children, she would tell them only that she had had a son but he had died. In that first session I asked

tentatively whether she felt that there was any link between her illness and her grief but she resisted this fiercely, angrily, saying that it would be like blaming Saeed, which was intolerable for her, otherwise it was criticism of herself, which was only slightly more bearable.

Through this resistance, I understood that a major task of the therapy would be to try to find a way to conceptualise and make links between her feelings about her illness and her loss; she seemed to need to them keep close but separate. In "Mourning and Melancholia", Freud (1917) describes the process through which Mariam has taken the loss of Saeed inside herself, so that he has become part of her and thus cannot be mourned. By identifying with the lost object in this way, directing guilt and shame at herself through the mechanism of her ulcerative colitis, she is also harming Saeed, according to Freud (1917), punishing him for leaving her. Mariam has unconsciously set up a distorted version of reality in which Saeed's suicide cannot be accepted. Her ulcerative colitis and refusal of the treatment that would rid her of the symptoms are a disavowal of his death and most importantly, of the way he died.

Implicit for Mariam in rejecting a psychosomatic link was the idea that if she was doing this to herself, she ought therefore be able to stop it and make herself better. Consciously, she desperately wanted to get better but her illness was connecting her to unprocessed traumatic memories. In Mariam's own words, she continued to feel like a victim and a failure for not having the capacity to effect change within herself. In the fourth session she told me sorrowfully, angrily; "I get worse and worse", and said that she "hated" herself for this.

My supervisor helped me to theorise my position in the therapeutic relationship as needing to find a way to think about these links because Mariam could not, with the aim of her being eventually able to integrate and experience emotions associated with the traumatic experiences.

Mariam felt persecuted and feared that her good internal objects would be taken from her. This was brought into our sessions through her angry feelings about her treatment. She often said that she was not being helped medically, had to wait, or attend multiple appointments. This made her furious with her second husband because they were unable to afford private medicine, which she imagined would have allowed her access to better treatment. In her theory of guilt and reparation, Klein (1948) suggests that links between external and internal danger situations are related to the unconscious fear of having destroyed the good object. Unconscious phantasies about having harmed the loved object lead

to guilt, which has to be experienced before reparation to the loved object can occur, a state that is associated with the depressive position (Klein, 1948).

B.5. Being believed – resisting interpretation

The absolute necessity of being believed became a central theme of the middle part of the therapy. Mariam had experienced a catastrophic failure by people in the past to believe her when she had told them that Saeed was in danger from his father. She explained that she had always “known” that he would harm their child. She says that he had bought Saeed the pull-up bar and rope with which he hung himself and she was certain that he put the idea into Saeed’s mind.

Therapy took on a pattern of Mariam attending for one or two sessions and then missing the next one or two. She never managed to come to more than two appointments in a row but would always telephone to cancel. I felt that she was letting me know that she needed me even when she could not face coming. This continued throughout the entire contract and often the reason given was that she felt too ill, or had clashing appointments. Towards the end she was able to tell me that once she had been unable to come because she had felt ashamed.

In the fourth session, as part of a discussion about how ill she was feeling and how difficult it had been for her to attend, she told me that although I “might not believe” her, she had had only two hours sleep the previous night. I felt that her need in that moment was for me to show her that I really did see how ill she was, so I said, “I believe you”. She was silent for a few moments then began to cry. After some time, I asked her if it was thinking about feeling ill that was making her cry, or something else, and she answered: “That you believe me”. Britton (1988) describes how a client’s need for agreement is high if they do not expect to be understood, reflecting “a desire for understanding from the primary object” (p57). I believe that trauma had led to Mariam’s experience of failing to be understood.

B.6. Trauma

Mariam’s memories of her abusive marriage, Saeed’s suicide and her current illness are experienced by her as traumatic and psychically fragmenting (Layton, 2008). In her study of psychological trauma, Herman (1992) describes how the core experience is one of disempowerment, suggesting; “...that at the moment of trauma, almost by definition, the individual’s point of view counts for nothing...The traumatic event thus destroys the belief that one can *be oneself* in relation to others” (p53). Britton (1988) suggests that the experience of being

misunderstood in such a fundamental way annihilates the possibility of being able to establish meaning for the self. The effects of the domestic abuse suffered by Mariam that culminated in the suicide of her son haunted her.

In these sessions, my dominant countertransference feelings were a sense that Mariam was searching for help, from the doctors, from herself and from me, but that she was not finding it. I experienced a counter-transferential feeling of the therapy being stuck. To illustrate this, in the fifth session, Mariam came feeling ill and furious, telling me about a medical doctor who had seemed to her to be refusing to give her an iron infusion for her anaemia, and in addition, she said that the doctor had repeatedly wanted to know what Mariam had been “told” about her illness by a previous psychotherapist. As I listened, I wondered what she was telling me with this story. I thought about whether she experienced me as also refusing to help her. I felt that I was being attacked by Mariam. Bion (1959) describes a psychotic part of personality that wants to destroy “anything which is felt to have the function of linking one object with another” (p87). My understanding was that the doctor’s behaviour had touched on two areas of unconscious pain for Mariam. She had experienced her as refusing to give her what she needed, and worse, as intrusive and disbelieving. Herman (1992) says: “Trauma forces the survivor to relive all her earlier struggles over autonomy, initiative, competence, identity and intimacy” (p52).

Now, I too was depriving her of something she needed, which was to help her to feel better. According to Winnicott (1971), the therapist has to be able to survive destructive attacks, and only by experiencing the therapist as an object ‘out there’, existing separately from projection, can change occur. Object destruction leads to subject recognition (although this is never permanently achieved, much like Klein’s depressive position) and this developmental goal is re-enacted in the therapeutic relationship (Winnicott, 1971). Benjamin (1990) suggests that mutual recognition may nevertheless be struggled against because the subject/other may disagree, and this is experienced as threatening.

Mariam then associated to a previous therapy, at the end of which she had felt that her reason for missing the final session had not been believed by the therapist. After listening to this, I said to Mariam that I felt that she was telling me to believe her when she told me things and not to impose my interpretations on her because when people did not believe her, the most terrible thing happened. I felt that Mariam’s illness and her grief were inextricably connected; her illness was allowing her to experience her grief.

B.7. Using supervision - containment

At first, I used supervision as a container for my own sadness and feelings of helplessness. In the first three or four sessions, facing what felt like an onslaught of grief, I was overwhelmed and deskilled by the level of distress that Mariam brought. I experienced what Herman (1992) describes as “countertransference helplessness” (p141) and felt unable to place my trust in the therapeutic relationship. I took these misgivings to supervision where we thought together about the importance at this stage of being able to contain and think about Mariam’s feelings about her illness and her grief, informed by Bion’s (1959) theory of containment of projective identifications.

Later, I experienced countertransference feelings of anger. I expressed these angry feelings in supervision. This enabled me to work through them safely outside the therapeutic relationship and offer them back to Mariam as an interpretation of her own anger at the hopeless situation she found herself in, in terms of her health and her experience of continuing, debilitating mourning for her son.

After the fifth session, in which I experienced Mariam telling me not to interpret her, but to believe her, I worked with my supervisor to try to incorporate her resistance into the formulation and therapeutic plan. We thought about how words had the capacity to be extremely hurtful for Mariam and of my reluctance to interpret as a projective identification (Klein, 1946). Although I had become more able to contain Mariam’s distress, I was now colluding with her with my own defensive avoidance of thinking about how painful inner experiences might be linked (Aron, 1991). My supervisor noticed that as I described my feelings of being reluctant to make links, how I felt that by doing what she had asked me not to – by working in the transference - I was in some way betraying Mariam. I understood from this that I need to be able to do exactly what Mariam could not, which was to use the transference to be able to think about her guilt, shame and distress.

B.8. Allowing links

In the sixth session we were able to experience for the first time together the full weight of the guilt and regret that she felt about her son’s suicide. It seemed to me that all the previous sessions had been working up to this moment, as though she had been rationing her distress, weighing up how much I was able to tolerate.

Mariam told me that the previous night she dreamt about Saeed for the first in a long time. In her dream she had asked Saeed why he hadn’t asked her

for help and he replied that he had come to her but she hadn't been able to help him. Mariam told me how this dream was related to events in "real life" when Saeed had asked her once if he could return to live with her. Mariam did not think that her father and older brother would allow it and she needed their permission. She was hesitant in responding to Saeed, a hesitation she felt that he must have picked up. She said that she had decided that if Saeed ever did ask to live with her again, she would stand up to everyone and insist that he be allowed to come, but he never asked again, and she said she hated herself. She said that in her dream Saeed had been alive and she felt happy, suggesting Klein's (1940) interpretation of an unconscious refusal to accept his death. I felt a constriction and heaviness in my chest that embodied the weight of her grief, shame and regret.

Mariam said that for twelve years she had been telling herself that it was not her fault but that she did not really believe this. She still felt like a victim of her ex-husband but did not want to be and wanted to know how to forgive herself. She felt devastated by the thought that Saeed would have been disappointed in her. I said that it seemed as though that she was never going to find a way to think about this in a way that was bearable for her. After this, Mariam became calmer and thoughtful, leaving long pauses between speaking. She wanted to know whether I thought that Saeed had forgiven her. She asked; "Why didn't I try, why was I waiting?"

I wondered if there was something almost sadistic in Mariam's cycle of self-punishment and that she was getting some unconscious satisfaction from it. Freud (1917) describes how the lost loved object is taken in and integrated with the ego so that self-criticism and hatred is also criticism and punishment of the lost object. Mariam's ongoing suffering through her illness and rejection of treatment may have afforded her a degree of unconscious "sadistic satisfaction" (Freud, 1917).

I suggested to Mariam that she seemed to be blaming herself both for what had happened and also for continuing to feel guilty about it all these years later. I hoped that this might offer a way to make a link between her grief and her illness, something I had struggled to do up to that point. I said that she felt sad and angry with herself for being ill. She agreed, then said she did not want to be a victim any more but didn't know how to get rid of the feelings of self-blame, hatred and regret. It felt as though the feelings of guilt and grief were unbearable for her to keep inside herself and she had to expel them but needed a place where she

knew they could be safely kept. Mariam said that did want to get rid of those feelings because her son was gone and she would like to forgive herself.

After a long pause, she said that she felt as though she was always waiting for something that might bring her hope, but that when she looked at it, she saw there was no hope. Mariam then sat silently for a minute or two, and appeared to be thinking hard. I thought about how sad this jettisoning of hope was for her. Freud (1917) describes “normal” mourning in which a “respect for reality” eventually returns (p244). And after a long pause, Mariam laughed and said that she had been in the waiting room when I had arrived that afternoon and that she had felt sorry for me because she was my first client. I responded that it was difficult to see how much pain she was in but that I was glad that she came. She said; “Thank you” and it felt as though something had shifted for her. Her phantasy that I would not be able to tolerate her pain had been made conscious.

B.9. Bringing anger and shame into the sessions

The content of our sessions changed after this. Mariam brought her feelings of disappointment at her current life situation. She had married again after coming to the UK but she and her husband were now financially insecure and he was also physically unwell. She was unhappy with the relationship and felt that once again any promise of happiness that she might have dared hope for had been lost. She was frustrated that other people thought that her life was materially good when in fact she felt that they were poor. It felt stifling to her.

She said that she had always been concerned about what other people thought of her and described how she felt deeply uncomfortable talking about the physical side of her marriage with me. I asked whether she was worried about what I would think and she replied that she wasn't but almost immediately said that yes, she was, wondering aloud why she had denied it. She said that if she was sad, people assumed that it was only for Saeed, but it wasn't always about him, she also felt sad for the circumstances of her own life. She was beginning to be able to feel sorry for herself and care for herself.

Mariam became increasingly angry in our sessions, saying that it felt as though her whole life she had been waiting for things to get better, but they never did, and she asked me whether I thought she was unrealistic to want this. She wanted to feel whole. As we were approaching the last two sessions, I said that perhaps she felt angry that I had also failed her; that the therapy would end and nothing would have changed. It did feel to me as though nothing had changed, and that I had not been able to help. My supervisor helped me to see that

Mariam's anger was itself change, and that I must try to continue to hold it for her for the remainder of our work.

B.10. The ending

Mariam's work will go on through the rest of her life. The task of coming to terms with her son's suicide can never be completed (Brice, 1991). We made it to the last session, and this felt like an achievement in itself. I did not want to let her go. She declined the offer of an onward referral within the service.

In our last session Mariam arrived with all her photographs of Saeed to show me. My initial response was a feeling of horror at the thought of having to see her dead child. It felt important that we look at him together. She sobbed violently and said she missed him. Klein (1940) describes how crying in mourning is a way of expelling bad feelings and objects, creating a greater feeling of internal freedom and giving the experience of sorrowful internal objects that share her grief and are therefore comforting, like "kind parents" (p359).

I thanked her for bringing the photographs. After about thirty minutes, she put them on the table between us, where they remained for the rest of the session. Mariam said that it was difficult for her to say goodbye, and remembered that she had never had the chance to say goodbye to Saeed. She said that she was sorry that she had given me such a sad and difficult piece of work.

Working in the transference with Mariam felt at times to be an imposition of my own ideas rather than a true mutual understanding. This ambivalence is recognised by Howard (2010) who sees it as a struggle for developing therapists to come to terms with their "power and significance" for their clients (p92). Hoffman (1983) says that the therapist works to let the client know that they are not so threatened by the countertransference that they cannot work, and are able to provide a relationship that departs from the client's usual transference-countertransference interaction. By thinking about what was happening in the space between us, what Symington (1986) describes as the truth that exists between therapist and client, I hoped that Mariam would begin to experience her inner world differently and start to heal.

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Section C: Combined case study and process report

“Focusing on process with a narcissistically injured client”

This case study and process report describes a six-month-long piece of work with a client who came to counselling following a medical diagnosis, because he wanted to understand the feelings of destructive anger and irritation that he experienced towards other people. From the beginning, he wanted to know whether his current unhappiness was connected to his mother having left him when he was three years old.

The extract presented in this report took place halfway through the contract after a supervision session in which I was helped to clarify the formulation and the transference-countertransference relationship. Up until this point, I had been finding it difficult to communicate to the client my understanding of his pain. My intention in describing this process was therefore to examine the extent to which I was able to translate the theory that was discussed in supervision into practice. It highlighted for me how difficult yet critical it is to strive for consistently empathic relating with a narcissistically injured client (Mollon, 1993).

C.1. Theoretical framework

For this case, I drew on my developing understanding of relational psychoanalytic theory. This approach emphasises a two-person psychology and a co-constructed view of the therapeutic relationship (Greenberg & Mitchell, 1983). Safran (2002) argues that the aim of therapy is to collaboratively focus on exploring the here-and-now transference and counter-transference with less emphasis placed on traditional transference interpretations of the drive and structural approach or object relations schools. The therapist uses their countertransference to understand the client's subjective experience (Greenberg & Mitchell, 1983). Clarkson & Nuttall (2000) describe this model of countertransference as all “feelings, fantasies and thoughts” that the therapeutic relationship produces in the therapist. It's theoretical origins lie with Klein's (1946) notion of projective identification as an unconscious communication (Clarkson & Nuttall, 2000).

Stern et al. (1998) propose that therapeutic change occurs through inter-subjective moments that occur between client and therapist and alter the client's

implicitly learned ways of being in relationship. Safran (2002) suggests that the aim of short-term relational psychodynamic therapy is to give the client a generalisable way of understanding their experience. This is achieved through the development of mentalizing skills; a stance also proposed by Allen, Fonagy & Bateman (2008) that emphasises attending to process over content and understanding that relating to others is reflected in mental states.

Relational psychoanalysis is theoretically pluralist (Greenberg & Mitchell, 1983) and Rizq (2010) suggests that this makes for a particularly good fit with the pluralist, constructivist and phenomenological epistemology of Counselling Psychology. For this case I have found it useful to integrate Mollon's (1993) idea of the "fragile self", which is based on Kohut's (1977) self-psychology. Kohut (1977) argues that a selfobject is formed when an infant internalises the adult carer's "experience" of them (p. 353). Mollon (1993) suggests that if a mother is unable to allow her infant's omnipotence, in what is essentially a failure of empathy, narcissistic injury will occur. This will result in an unavailable selfobject and is expressed in narcissistic characteristics such as absence of self-esteem, high self-consciousness and underlying unconscious shame (Mollon, 1993).

Bollas (1987) also uses the concept of the client's relationship to the self as an object. He describes the process by which infants transfer to themselves aspects of maternal (or other) care and become their own internal object, which is conceptually similar with Kohut's (1977) selfobject. Thus for Bollas (1987), the mother becomes the "transformational object" (1987, p60) and he suggests that the goal of the therapeutic relationship is to allow the client to express his relationship with himself as an object and through doing so, "receive his own discourse" (p62).

C.2. Context, referral and presenting problem

The client, James², self-referred to an NHS Primary Care counselling service at the suggestion of his GP following a diagnosis of ulcerative colitis. Psycho-neuroimmunology research links ulcerative colitis with chronic psychological stress (Goodhand, Wahed & Rampton, 2009). Stern (2010) describes the need for psychological help, in his case psychoanalytic psychotherapy, for patients with

² All names and biographical/personal identifying details have been changed throughout in order to preserve confidentiality.

bowel disorders, which he says are often characterised by feelings of shame, sadism and disgust. He suggests that the goal of such therapy is to provide patients with the opportunity "...to make links between bodily symptoms and their inner worlds" (Stern, 2010, p130).

After a telephone assessment with a service wellbeing advisor James was referred to me for psychodynamic counselling. In the telephone assessment he said that his mother had left him when he was a three-year-old and he wanted to use the counselling to think about how this may have affected him. He particularly mentioned the strong feelings of anger and irritation that he often experienced. He completed measures for depression and anxiety and his levels of risk were assessed and considered to be low. He mentioned that he drank around 40 units of alcohol a week and acknowledged that this was probably excessive and that he planned to reduce it.

C.3. Personal details and the first session

When James arrived for our first session, I met a tall, slim man in his forties with a long melancholy face. His manner was understated and he seemed guarded. He talked about the diagnosis of ulcerative colitis about which he did not seem to know very much, nor wished to. He said only that he was afraid that the condition would worsen and that he could die from it, which he found frightening. The symptoms of the disease were embarrassing for him.

He said that he had had a lot of stress in his life over the previous two years, related principally to a financial matter. He spoke of his emotional pain in a bemused, almost affectless, detached monotone. The content - his feelings of anger and bitterness - were so at odds with the manner of his talk that I found I was simultaneously appalled and fascinated. It was as though he was telling the story of another person, and I felt gripped by the narrative. Later, I thought that these counter-transference feelings reflected his critical need to keep me interested so that I would not leave him. He unconsciously understood that people were drawn to this damaged part of him, yet he needed to hold them at arm's length, where he could not be hurt if they left.

His rage was most often directed at strangers and he said that sometimes he felt as though he wanted to hurt people, although he had never acted on this. Instead

his destructive impulses appeared to be directed inwards, on his own body. At the end of the first session he said that he had “liked” taking about his difficulties and seemed suddenly cheerful in what I felt was quite a sadistic manner, as though I had been left with something unpleasant.

C.4. Assessment

Hinshelwood (1995) suggests focusing a psychoanalytically informed assessment on the client’s descriptions of object relations in his present life, his early years and the therapeutic relationship. James was at the end of a complex divorce settlement, having separated from his wife seven years ago at her instigation. They had three children; two girls and a boy, the youngest girl Kate, who is 16, was the only “normal” one, according to James. He said that the middle child Gemma was “mad like her mother”, and the oldest is a boy, who is 22, whom James described as not very bright and always getting himself into “trouble”. James was also a grandfather, although he had never seen the child, a baby his son had with an ex-girlfriend from whom he was estranged. James saw his children only rarely, seeming to find them very difficult to be with. He had spent many of the years when the children were young working for weeks at a time abroad, and said that he found this escape from family life a relief.

James has a partner of five years, Anne, a widow with two boys. He felt supported and loved by Anne, and was committed to the relationship but was constantly on guard for signs that she may leave him. Anne’s two fatherless boys irritated James intensely when they were boisterous or loving. If they showed affection towards him, he said that he felt that he could not stand it; it made him “squeamish, anxious...like I can’t watch it, I want it to stop”. He said that he did not want to be close to them, although they were “good boys” and he felt sorry for the fact that they had lost their father, he was not interested in taking on that role. Although he lived with them for some of the week, he would not let them kiss him goodnight at bedtime, insisting instead that they shake hands.

His now-dead Grandparents, his youngest daughter Kate and his partner Anne, were the only good objects in James’ life. On the whole, he experienced other people as persecutory and difficult to understand. He was utterly perplexed by his ex-wife and two older children, feeling attacked and frightened by them. He could not understand their behaviour, which seemed chaotic to him, and he described in

horrified terms their disregard for property and the family home that he had carefully created with the proceeds of his work. He told me of a current fantasy that he had of going to live on a remote Scottish island, completely alone.

In the first session, James told me that his mother left him when he was three years old. He said that he remembered the morning that he was told that he would be going to stay with his (paternal) grandparents. He was an only child and from that day until he left home in his early twenties, he remained with them. Initially his father also lived with James and his grandparents, but when James was six, his father also left to work abroad, returning from time to time, and later remarrying. His mother never came back and he did not hear from her again, except once when he was 12, when she appeared and took him out for the day, promising that they would go out again soon. He remembers her buying him a present – a slide rule that he chose, and feeling intensely happy about this, but he never heard from his mother again. He wondered whether she was still alive. When I asked whether he had asked his grandparents or father about her, he said that he never did, and could not think why, saying that it had never occurred to him. At first, James had idealised his father but now he felt disillusioned and disappointed by his lack of interest in him ever since he had remarried and had two more children when James was still a child.

His most frequent fantasy that he brought to the sessions in relation to his mother was that she had died and left him money. He described his grandparents as kind but old-fashioned in their approach to child-rearing, and described his childhood as “happy”, although it seemed that he spent most of his time playing alone. The family were financially comfortable, and money is important to James, reminding me of Bollas’ (1987) idea of the transformational object, in which money and things can become transformational objects, just as people can, and how in seeking out transformational objects, the emotional experience of the early transformational object relating is recreated.

C.5. Rationale for psychodynamic counselling

James wanted to know whether his present difficulties might be linked to his early losses, which pointed towards a psychodynamic approach. James met the conditions that Lemma (2003) suggests are necessary for psychodynamic counselling. These include adequate ego strength, as evidenced by the fact that

James functioned in his daily life and was able to work and maintain some level of relationships. He demonstrated impulse control and frustration tolerance by not acting on his angry fantasies. He was able to consider tentative interpretations without regression (Lemma, 2003).

C.6. Contract and psychological counselling plan

Initially, we contracted to meet weekly for 5 sessions because I was due to take my summer break. I suggested that we use this time to try to gain an understanding of his problems and to decide together at the end of it whether to extend to a longer piece of work. I was then able to offer a further five months of counselling to James. I found working with James compelling and believed that he would be able to benefit. I thought about how this was a likely to be countertransference response to his unconscious experience of feeling that he could not be left.

C.7. Formulation

James' affects, behaviour and defences suggested narcissistic injury during childhood (Mollon, 1993). This formulation presumes that James did not experience an empathic response to his primary narcissism, leading to an unavailable selfobject (Kohut, 1977). Mollon's (1993) account of disturbances of the self describes James' de-personalisation, helplessness, self-consciousness, shame and rage. These feelings defend against a disorientated self-response to experiencing others as un-empathic (Mollon, 1993). In this state, his awareness of himself as seen by others is foremost in his attention and his subjective experiencing self is pushed into the background.

I also found it useful to think about a Kleinian formulation of schizoid object relating that posits that James' unconscious phantasies are of having destroyed his mother (Klein, 1946). Klein (1946) describes how in schizoid object relating, there is a "shrinking from people in order to prevent both a destructive intrusion into them and the danger of retaliation by them" (p13). This is described by Lemma (2003) as a bad internal object that is experienced as un-survivable; to protect the ego it has to be split off and obliterated internally, or projected outward.

These two formulations are consistent, according to Greenberg & Mitchell (1983), who argue that narcissistic and schizoid formulations have been applied in the literature to broadly similar patients and reflect not different causes of distress, but the affiliations of the theorists who use them. Winnicott's (1965) theory of psychosomatic illness also suggests that James' medical symptoms function as defensive splitting, protecting him from psychological pain.

C.8. Key content issues in the therapy

Shame

After a few sessions, James revealed his uncomfortable feeling that his family may have always withheld information from him about the reason for his mother leaving. In an early session, he tentatively offered a fantasy; that a mother would only leave her child because the child was bad. He based this on his observations of mothers, telling me in a bewildered tone: "Mothers just don't *leave* their children". He said that he could not understand why his mother had not contacted him in all these years. He said haltingly; "...maybe there was something so...wrong...with having me there, or something...perhaps". I felt that James unconsciously experienced himself as a monster who drove his mother away and destroyed her. Mollon (1993) says that believing a parent has gone because the self is not loveable is "mortifying" and narcissistically wounding (p51). When I observed how terrible it was for him to feel that he was bad and that this was why his mother had left him, he reported a dream-like sensation he used to have as a very young child in bed. He said that while still awake, just before he fell asleep he would feel as though the door and the walls of his bedroom were closing in on him very fast, then going away and coming back in; the "room seemed to be coming in on top of me" and he remembered how frightened he felt.

After telling me about this sensation, or dream, James described his fantasy that his mother could have died and left him money, and then changed the subject to football. After a pause, he asked me whether we were getting closer to a cure. I was taken aback by the abrupt change in direction and asked him what he thought we needed to "cure". He laughed then and said that he had just been joking, which gave me an opportunity to reflect to him that when we talked about his mother and difficult feelings were in the room, he would change the subject, turning it into a joke about what we were doing together. I wondered what it might be like for him if we were to stay with those difficult feelings and he replied that he

“might start crying or something” and that he tried not to think about things too much in case he became upset “or something”. I wondered what the “or something” was for him. He then said that he did not see the point of getting upset and that he wasn’t even sure what there was to be upset about.

After returning from a break in the therapy, between weeks five and six, James talked about his fear of dying from his ulcerative colitis. He said that at least if he died, he would not have to go to other people’s funerals, and therefore he would not have to be left by others. He worried about what he would do with his possessions if he died. I felt that he had found the break disturbing, and was telling me that he was wondering who to give his thoughts and feelings to. He valued them and wanted them to go to the ‘right’ people.

Being held in mind made James uncomfortable and embarrassed and he experienced being seen by other people as shameful. A recurring theme from school and adult life that he described was of feeling acutely self-conscious. He felt excruciatingly self-conscious about meeting people and could not bear his family talking about things he had done in the past. I said that it was as if he could not think about himself. He described a feeling of dissociation that he said was like watching himself as if he was in a film. I felt that his experience of shame meant that James experienced relationships as completely unpredictable, vulnerable to rupture and endings (that he might somehow be the cause of) and that it was difficult for him to approach himself in his mind.

His unconscious fear of abandonment was enacted in two ways. One was in a seductive transference relationship in which I experienced him as a profoundly compelling storyteller. He would ask whether I thought he was wasting my time (was I also going to leave him?). I felt that he was unconsciously working to maintain my attention through a projective identification (Klein, 1946). A parallel process was being enacted in my need to take the work to supervision frequently, where a good supervisory alliance helped me to think about transference and counter-transference were being enacted in the therapeutic dyad (Howard, 2010).

The second way that he avoided me was through contempt. He would tell me with a smirk, that he liked having “his own shrink”. I felt that he was avoiding any emotional contact with me and simultaneously making me feel toyed with, diminished and unimportant, perhaps the way he did in relationships. I felt

uncomfortable and irritated and wondered to myself whether we should continue with the therapy, whether it was helpful for him.

Being a son and a father

James's relationship with his father was another source of pain for him. He described how as a boy, his father and uncle had included him, such as during times when they would work on their cars in the garage of the family home. He remembered how he had loved being with them, hearing his uncle's stories of nights out with girlfriends, and thinking to himself that one day he would be "just like him". His father remarried after a few years and James said that his stepmother had never liked him. He would spend some of his school holidays with them but remembers being left alone for most of the days while his father was at work. He felt that nobody was interested in him. His relationship with his father was being painfully recreated in his relationship with his own three children. He increasingly made links between his experience of being a son to a father whom he experienced as uninterested in him and his own shortcomings as a father. In session 10 he said: "My dad was a rubbish dad, I've been a rubbish dad". It was one of the few times when he appeared to be close to tears. It was as if he did not know how to be a father to his children and found his role in their lives confusing. His partner had never met his children and they did not know about her, although he said that she desperately wanted to meet them, he was unable to reconcile his present and past lives.

Anger

James described feelings of anger and irritation frequently. Often this was directed at his partner's two sons. In session 8, he said that he physically could not stand it when they cried. He could not allow himself to feel sorry for these boys, I felt, because that might mean that he would have to extend his sorrow towards himself, who was not just fatherless, but motherless too. He would also describe how anybody who was rude, and bad drivers, would also make him furiously angry. He could not tolerate people who seemed unpredictable, describing how a drunk or perhaps mentally unwell man on the tube for instance made him feel unbearably embarrassed and almost desperately violent towards the stranger. He said that he "could not cope with weird situations". It seemed that the idea of a mind so visibly disordered, or in pieces, was intolerable to him.

C.9. Difficulties in the work

This anger and fear came into the transference after the summer break when James excitedly described to me, in more vivid terms than he usually spoke, his violent fantasy of attacking “chavs” or “hoodies” on street corners; he wanted to “get revenge” and “take out some of these people”. I felt deeply uncomfortable and anxious in the countertransference, as though I was the one being taunted, attacked in some way, and that he was angry with me. It felt as though I was trying hard to reach James, but was failing, causing me to experience my own shame at my shortcomings as a therapist.

Around the mid-point of our six-month contract, I began worry that I was unable to work in the transference with James. I felt compelled to listen only, as though I was being kept out of the relationship, unable to let him know that I could see and hear how much pain he carried with him, unable to interpret my empathic countertransference effectively, effectively paralysed by his rage and contempt. I found it difficult to think about and describe to James what was going on between us in the sessions. I realised with a shock that in our relationship I felt voyeuristic, and that I was being drawn into participating in James’ sadistic attacks on himself. I had an image of an empty space inside James, something missing at the centre of him that was being kept that way deliberately.

C.10. Changes in the formulation

Safran (2002) suggests that a formulation should emerge out of a cycle of understanding situated in the therapeutic relationship. My feelings of voyeurism led to a centrally important development in the formulation. Mollon (1993) suggests that the therapist’s empathic failure will be experienced by the client as fatally disorientating, leading to a sado-masochistic element entering the therapeutic relationship as the client’s shameful self-conscious feelings come to the fore and are projected.

A few sessions before another scheduled break, James told me that he was pleased and proud of the fact that he had not “lost” his mind. That he would “hate to lose his mind”. I understood from this that he experienced this as a very real possibility. He felt that he might literally become mindless, like the drunk man on the train, and this thought was horrifying to him.

C.11. Lead in to the session and extract

This extract is from session 13. James has been describing how he experiences his eldest daughter, Gemma (22), as “manipulative”, illustrating how he experiences people as persecutory. I was trying to hold the formulation in mind but not impose it on him, as Casement (1985) cautions. My aim in the session is to reflect James’ process to allow him to experience a greater sense of integration of the subjective and objective self (Mollon, 1993).

C: Client

CP: Counselling Psychologist.

Comm: Commentary

Extract

C1: She [Gemma] phoned up the other week, last week and she keeps in touch with me, she phones, sends me texts or phones up and she phones me up and then she’ll be talking and I can tell within 30 seconds what sort of, the way she is. She told me she hadn’t got any money and she hadn’t got any money for a week and she really needed some money because she was at the, almost overdr-, past her overdraft and she’s in a lot of debt anyway, she doesn’t give her grandmother any money. She lives with her grandmother so, she was telling me this, but I just didn’t even think well, my first reaction was, I don’t quite trust you with this, I think there’s something going on because I just find her like I think she’s, all the money she probably spent on makeup or dresses or something like that, I don’t trust, I don’t trust her in a way about it all, but eventually I said ok, how much are you overdrawn, right what’s, ok, so, I sent her two hundred pounds and that would clear her overdraft and give her a hundred pounds for the week, but it felt, I was more thinking I don’t know if I trust her about all this sort of thing, I’m not sure what’s going on with her [Sighs heavily].

CP1: That feeling of not knowing what somebody wants, or what’s really going on, I’ve noticed that’s a hard thing for you isn’t it, it’s a difficult feeling for you to have.

Comm 1: James’ description suggests Mollon’s (1993) un-empathic internal object. His deep sigh tells me that he is struggling. In the counter-transference I

feel resistance to the experience of thinking about this. I am trying to describe his conflict in terms of the emotions he is currently experiencing. This interpretation could have been improved if I had situated it in the here-and-now, such as: "I'm noticing that this is a difficult feeling for you to be having right now".

C2. [Sighs, and speaks very softly] Yeah.

CP2: It makes you feel lost in some way, like you're not sure what you, what's expected of you.

Comm 2: I feel that James experiences not knowing in relationships, either how to feel or what to do and say and like now, he becomes excessively self-conscious, concerned with how he is being perceived. This suggests an inability to empathise both with others and himself, reflecting Mollon's (1993) theory of narcissistic disturbance in clients who have lost parents in early childhood. My intention is to describe his process to promote mentalizing so that James experiences himself subjectively (Allen et al., 2008). This intervention could have been improved if I had linked it to what was happening between us in the therapeutic relationship (Safran, 2002).

C3: [Sighing] Yeah, I, I just have a bit of a distrust in what Gemma does, and I can quite believe she has no money, but I find it very hard to offer any sympathy or show any emotion with her.

CP3: Is that what's difficult, is that what bothers you, 'cos as you were talking I was thinking it wouldn't, for a father not to trust his daughter not to spend her money on clothes and makeup, that wouldn't be unusual would it.

Comm 3: His voice breaks a little when he says "but". He is telling me something important about the way he feels about his daughter and also himself. I believe he is saying he can't be sympathetic because it's too painful for him to think about these feelings. I am thinking how unconsciously they are too threatening to his psychic integrity so he defends himself by shutting down.

I hypothesise that he projects his bad internal object into Gemma, which now threatens to come back and attack him (Klein, 1946). He experiences Gemma and himself as "a secret and undiscovered murderer" (Greenberg & Mitchell, 1983,

p.127). *I think he is letting me know that he wants sympathy and emotion from me and I'm concerned that James experiences me as insufficiently empathic here, exacerbated by that fact that I interrupt him. It would have been better if I had said nothing at this point and allowing him to stay in touch with his feelings. In describing Klein's (1946) theory of object relating, Lemma (2003) says that a bad internal object tends to make us feel criticised and suspicious. This seems to be reflected in my process here too, making me momentarily lose contact with him here.*

C4: [laughs] yeah, I know, yeah.

CP4: But it's the next stage isn't it, it's this idea that you don't let yourself feel anything for her [C1: no] I think, which is possibly the difficulty.

Comm 4: He laughs obligingly but I wonder whether this is compliance (Winnicott, 1984). I feel sad that my response to him was un-empathic and am wondering why this is happening. It would have been better if I had been able to reflect this to him by saying something like, "Just then, it seems that I wasn't understanding enough of how uncomfortable these feelings are for you". Mollon (1993) warns that empathic failure must be guarded against when working with narcissistically injured clients because they "have internalised the absence of an empathic response in the form of the presence of an un-empathic internal object" (p.60).

C5: It's wor-, worn me down a bit, from when she was maybe 12 or 13, and I think her Mum was also involved in this whole mental situation where things were going ridiculously bad, phoning up ambulances, phoning up police saying she was being abused, all these sorts of things going on, and I was like, and I really wanted to resolve this and it made me have a knot in my stomach when I got a phone call, worried it was about Gemma and my, really really concerned about her, wanting to know if I could help her, we went to people about it and, then she'd be out drinking and smoking, we bought her a new bike for Christmas, within two days it'd been stolen, she'd been out with some lads and they'd taken the bike and then suddenly I just thought, enough is enough, I really don't want to be involved in this whole situation, then my wife, had enough and then I just said, right, that's it.

CP5: It's, you seemed afraid as you were talking then, when you were describing those situations with Gemma, and it seems that Gemma touches something in

you which is very, very uncomfortable and frightening, something about her behaviour elicits a response in you which is, is, like fear.

Comm. 5: I am thinking that the frightening bad object is perceived unconsciously as both in him and Gemma. Greenberg & Mitchell (1983) say that in Kleinian theory loss is experienced as having been caused by destructiveness and as retaliation for infantile hateful behaviour.

In response to me reflecting the difficult feeling of not caring for his daughter, James reels out a list of Gemma's activities, showing how overwhelmed he is feeling. He also links these feelings to his ex-wife, and I hypothesise that before Gemma, it was probably her who was perceived as containing the bad object and therefore as attacking. I experience how scared James feels as he describes Gemma's transgressions, how out of control it all seems to him. He breathes out heavily when I say "afraid" and again makes a noise when I say "uncomfortable and frightening". Mollon (1993) suggests that helplessness is related to shame.

C6: It was a lot of fear for me, when things were going like that it was just a start of my life when suddenly I'd had this family and everything was nice and everybody was happy and I had a lovely home and then suddenly things suddenly changed in the family and it made everybody really upset in the family and it, it just got out of control and, and I'd just, you know, try and resolve things but I'd go away to work in Ireland and then got phone calls about the police had been round, she's been doing this, she's doing that, and that's like oh no, why, why is it happening, and er, so I've really, after all of this going on for a number of years, and then still hearing things later on for example, about a year ago, Joan [his ex-wife] said to me oh yeah, "she's got some er, pen-pals she writes to", and "pen-pals yeah", "yeah, they're in prison", "they're in prison! [laughs disbelievingly], writing to people in prison", so I said, "What's this about?" "Oh they're alright, there's nothing wrong with them". "What are they in prison for?" "Oh it's nothing." [inaudible] Oh, oh, no, [laughs sadly] I don't want to hear any more of this rubbish. So, er, then I hear things like, oh yes she's, "I don't live at Grandma's any more, I live at this, this guys house". I said, "this guys house?" "Yeah, this guy he's older he's nice, he's really nice." "Is he your boyfriend?" "No he's not my boyfriend." "Is he gay?" "No he's not gay." I said, "How old is he?" "Thirty-six". Oh, I really don't need to hear this sort of thing and it's like, I'd probably shock you if I said I've really become so numb to it all, and lack of emotion.

CP6: You think I would be shocked if you said that.

Comm 6: The word "suddenly" is being used a lot, suggesting James felt bewildered by what was happening. He sounds very sad as he takes up the theme of fear and things being out of control. His description suggests that just as he was beginning to feel protected from the bad, destroying internal object through his material possessions and family, it came back to attack him. Gemma pen-pal prisoners are the bad attacking things "out there". He exclaims twice how he "doesn't want to hear this", telling me it generates feelings in him that are intolerable. His comment about how I would probably be shocked suggests that in the transference he believes I find him unacceptable. I respond by paraphrasing because if I say nothing he might experience me as assenting. Allen et al. (1998) suggest that a better response might be to say that I was not aware of feeling shocked and then explore together how he has reached this conclusion.

C7: I think you'd be shocked if I said I'm that numb to it all.

CP7: You don't care any more.

Comm 7: I interrupted, cutting him off. In the countertransference I am experiencing his transference need for me to contain his feelings (Mollon, 1993) but I interrupted his process in my attempt to rescue him and make myself feel better. This is an example of my agenda impacting on the session. It would have been better if I had waited to see whether he had more to say.

C8: It feels like that.

CP8: Yeah.

Comm 8: In C8 he agrees and from the tone of his voice this does not seem to be compliant transference. I feel relieved that my too-early intervention in CP7 does not seem to have caused too much damage to the therapeutic alliance, but I am still wondering what might have been said. This reflects the ongoing tension I am experiencing in trying to adopt the active stance advocated by Allen et al. (2008) and leaving James enough space for his unconscious to work.

C9: I could see, I could imagine her being a prostitute, I think, it wouldn't surprise me in the slightest, you know, I'd think, fair enough, s'alright, whatever you wanna do, I've told her that once she tried this emotional thing, I went round to my mother-in-law's house, who's still very friendly with me and I'd mentioned that I'd walked into the house and then suddenly there was this, oh no actually it was another time, there was a big argument about something and I'd heard, Joan's mum, mother-in-law said, "Oh yes she's been terrible recently she's been ridiculous and so badly behaved I've really had enough of this whole thing James", and I was like why, what's going on, what's going on, anyway next minute there's a big kerfuffle and there's all this shouting and Gemma's there saying, "I don't need to live here, I can go and live, I can go and live with my friend, my friend", whatever he's called, such a body, and I said, "Fine". "Yeah, he'll give me money if I go up to stay with him." I said, "Fine". "Yeah I'll go up there now". I says, "Come on, I'll give you a lift up there". I would have taken her up there, I really don't care, but I've been driven to that and it, it's just so...I, but, the same time, I've seen bits of her where she's been so nice and I've just had a conversation with her and she's talked and she's been normal, I mean it might sound daft to say she's not normal but when you've seen what I've seen.

CP9: To you it feels not normal.

Comm 9: He is struggling to contain feelings about bad and good objects being contained in a person (Klein, 1952). I am thinking that James cannot tolerate ambivalence in relationships, a reflection of his paranoid-schizoid position. I interject too soon in my anxiety for him to experience me as empathic. The emotion is evident in his voice and the atmosphere in the room feels highly charged as though the feelings he is experiencing are almost overwhelming. I think that I am also feeling at risk of being overwhelmed and am making an intervention to ground myself.

C10: These aren't normal things and I know teenagers are teenagers, she's not a teenager any more she's 22 but for the level of the things I've seen, an-, are far beyond normal, or teenage things. I could accept, I could accept somebody having a house party, something like that, maybe a bedroom getting wrecked or you know I could accept somebody sm-, banging the family car or something, I could accept all normal things, I could accept catching her smoking, I could accept

her smoking, I can accept boyfriends and all this, I've no problem with that, I accept things like that, but when it's not normal.

CP10: I, I sense that you feel so-, somewhat persecuted by it, almost as if she's doing it to hurt you?

[James breathes out heavily twice]

Is that how it feels?

Comm 10: As Casement (1985) suggests, I am using countertransference to listen for James' unconscious communication and I feel that he is afraid of his daughter. He experiences a rigid distinction between normal/not-normal and acceptable/not-acceptable. I am thinking about how right now for James there are no in-between feelings so a person/object is either good or bad but not both (Klein, 1946). James is telling me that he experiences his daughter at these times as intentionally harmful and therefore dangerous. When I name the feeling for him he breathes out hard, as though he has been holding his feelings and is now letting them go.

C11: [Breathes out] I felt, that, that's what I think um, you're right, absolutely right, the manipulation, it seemed to be wanting to get this reaction and hurt people around her, it seemed to be hurting people that she got the kicks from.

CP11: And that, that's disturbing for you.

Comm 11: He sounds dismayed but less frightened than before. I am listening for compliance and a false-self (Winnicott, 1984), trying to maintain the focus on James' process by interpreting feelings caused by the idea that his daughter wants to hurt people. I am mindful that James has had fantasies of hurting strangers deliberately and I am thinking about the formulation and the fact that in the future I may want to make this transference link to him.

C12: That is very disturbing

CP12: The idea that she wants...

C13: To hurt people.

CP13: Hurt people.

Comm 12: I feel that it is still too soon to link his feelings about Gemma to himself and I resolve to hold on to this interpretation. I decide to continue reflecting James' process so that by subjectively experiencing his feelings about Gemma, he will begin to experience more understanding towards her and himself.

C14: And it's true, that is it, that's what we're wanting to get to, she hurts people around her and she seems to relish it, she seems to enjoy this fact that she can make people unhappy. So I've had enough unhappiness really in my life and I don't want to accept any more of that and I don't care, this well, Anne goes mad, "you don't care, how can you say that about your daughter, you don't care", but.

CP14: It feels like you *can't* do any more for Gemma.

Comm 13: In the countertransference I feel he wants me to accept his feelings and reassure him that he's not a monster. At this moment Gemma contains the destroying object through projective identification. By not caring, he is splitting off the feelings and defending himself (Lemma, 2003). I stay with my plan of promoting mentalizing (Allen et al., 2008), using my feeling that James helpless about Gemma, and describing this to him in order to provide him with an experience of subjective understanding.

C15: I really couldn't, I couldn't have seen the point when I could have done any more myself or, even my wife. I think there's something between my wife though, I think she's, my ex-wife is slightly, something there, not quite right as well, a bit mental, so between everybody it just got to the point, I thought, enough's enough, I need to walk away from all of this, before I go, before I lose my mind, or.

CP15: It made you feel like you would lose your mind if you stayed. [James sighs deeply].

Comm 14: I am reminded of previous sessions in which he spoke with bewilderment about his ex-wife's behaviour. My countertransference feeling is that it is safer for him to blame her for Gemma's behaviour, defending against feelings of helplessness. I am thinking about how Mollon (1993) suggests that helplessness and rage are narcissistic affects that defend against shame, and

how these helpless feelings make him feel as though he will go mad, like Winnicott's (1984) concept of annihilation.

C.12. Discussion

This extract demonstrates how critically important it is to strive to prevent even momentary failures of empathy when working with a narcissistically injured client because such clients are unconsciously highly sensitised to others' perceptions of them (Mollon, 1993). The clearer formulation helped me to have a better understanding of James' subjective experience although it did not prevent me from losing contact with James' when I experienced a particular counter-transferential pull to rescue him. I believe that this was because I became overly concerned with applying a particular model, in this case, mentalizing theory (Allen et al., 2008), which meant that my agenda impacted negatively on the session. I have been struck by the compatibility of the concepts of narcissistic injury of Kohut (1977) and Mollon (1993), Klein's (1946) theory of schizoid object-relating and Winnicott's (1984) ideas about a mother's inability to contain infant omnipotence.

Through supervision, I gained a clearer understanding of the enactment of seductive transference within the therapeutic dyad and my role in this. I had a clearer sense of a counter-transferential feeling of being seduced and will hold this in mind in future sessions. This helped me to reflect on James' need to keep people in relationship, and the anxiety he experiences when he perceives a failure to do so. I reflected both in supervision and personal therapy on whether I may unconsciously invite a seductive transference from clients, effectively colluding with them.

The focus for the remainder of the contract would be on continuing to work with process at moments in which James experiences a lack of subjective understanding and feared abandonment. My intention was to use the ending to explicitly explore ways in which James can tolerate ambivalence and imperfection in relationships. Towards the end of the contract, James was able to express the anger and disappointment he felt about his father now, and was finally being to mourn the loss of this hoped-for yet always disappointing, relationship. He nevertheless continued to experience a sense of guilt at the idea of criticising his parents.

He had begun the therapy with no expectation that anyone would be able to manage his feelings. However, in the penultimate session, James was able to tell me how sad he felt about ending, and that he was dreading the last session and was thinking about how he would feel at ten to eight the following week. I offered him a follow-up session for three months after ending and his mood brightened instantly. It was as if the fact that he would continue to exist for me, although not being physically seen, was enough for him to feel that he could survive being left at the end of the therapy.

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Section D: Empirical Research

Understanding “altruistic” kidney donation – a psychosocial study

D.1. Abstract

The aim of this study was to analyse how prospective altruistic kidney donors construct their decision to donate, and to explore meaning-making, subjective experience and practices that are made available to the donor and others through discourse. A genealogical approach to existing literature was taken.

A multiple-case study design and biographical-narrative, semi-structured interviews aimed to produce text for analysis on two levels. These were; the social implications for subjectivity and practice, and a tentative, psychodynamic theory-driven explanation of the participants' psychological investment in the discourses they used. Six prospective altruistic kidney donors were interviewed.

In-depth discourse analysis integrated Foucauldian, psycho-discursive and psychosocial approaches. Psychodynamic theory was applied to sections of the text in which participants seemed to have particular emotional investment.

Discourse analysis generated three major discursive themes: other-oriented, rational and self-oriented discourses. Participants used discourses to position themselves as concerned with the needs of the recipient, to resist questioning and criticism, and to demonstrate the rationality of donating. Participants' own needs were largely rejected. Psychodynamically informed analysis suggested that altruistic donation was experienced by donors as compelling and could be theorized as unconscious communication.

Results suggested that using the term “altruistic” for living, non-directed organ donation constrains available discourses, severely limiting what can be said, felt, thought and done by donors, clinicians and the public. This study demonstrated the compatibility and usefulness of counselling psychology and psychosocial methodology when it is applied to the interface between the individual, the clinic and society.

D.2. Introduction

“While some of the claims made for altruism may be overblown, the notion of altruism as underpinning important communal values expresses something very significant about the kind of society in which we wish to live” (Nuffield Council on Bioethics, 2011, p132).

Altruistic kidney donation – the transplantation of a living, anonymous donor’s kidney to a stranger on the transplant waiting list – poses an ethical dilemma for health professionals and regulatory bodies tasked with governing organ donation in the UK. Whilst kidneys for transplant are much in demand, there were more than six thousand people on the active transplant list in January 2012 (NHS Blood and Transplant, 2012). The practice of accepting an organ from one individual to improve the health of another forces society to confront a number of important issues. These include our understanding and beliefs about the relative integrity and inalienability of the body, with far-reaching implications for the increasingly technologically driven nature of medicine, the values we place on life and death, the way in which we conceptualise the self in relationship to the physical body, and importantly for the discipline of Counselling Psychology, the extent to which we perceive ourselves as responsible for each other, the ways in which we think and feel about ourselves and our relationships to others.

The aim of this study is therefore to explore how altruistic kidney donation is constructed in its social and individual contexts in order to try to understand the various subjectivities that are brought into play. Martin (2010) argues that Counselling Psychology research needs to generate theory that can be applied in the various situations in which the discipline is practiced, always with the goal of contributing to the therapeutic relationship and outcome. I hope that by addressing these issues this research will contribute to the continuing development of a distinctive Counselling Psychology ontology, with its emphasis on understanding and theorizing subjectivity, inter-subjectivity, and ethical and philosophical assumptions about the nature of interaction between the individual and society (Martin, 2010).

Although practiced outside the UK since the 1990s, altruistic kidney donation has been legal in the UK since September 2006. In 2007-8, ten altruistic donations were approved. By 2010–11 this had risen to twenty-five (NHS Blood and

Transplant, 2012). The risk to the living kidney donor is statistically low, and is given as somewhere between a 1 in 3000 and 1 in 6000 risk of death and a 2 - 4% chance of major complications from surgery (Human Tissue Authority, Guide for Transplant Teams and Independent Assessors, 2011). The Human Tissue Act 2004 requires all living organ donations in the UK to be approved by the Human Tissue Authority (HTA). Consent from the HTA depends on certain conditions being met: No reward can be given to the donor; there must be informed consent, and an interview with the donor has to take place.

In its guidelines, the HTA instructs health professionals that: "*Psychiatric assessment is a necessary part of the process to ensure fitness to donate...Early psychiatric assessment is recommended to ensure there is no relevant psychiatric or psychological illness*" (Human Tissue Authority, 2011, 51: p15). The same document sets out the legal requirement for the assessor to: "*Be satisfied that the donor has no evidence of current or past mental illness that affects their ability to donate altruistically with full informed consent*" (Human Tissue Authority, 2011, 93: p.27).

Contemporary medicine aims to operate according to a rational system of ethics that incorporates moral intuition or feeling about decisions, as well as reason, and is centred, ethically and legally, on the patient's "best interests" and autonomy (Hope, Savulescu & Hendrick, 2008, p34). These rights and principles are applied equally to the altruistic kidney donor as to the potential recipient of the kidney. The use of the term "altruistic" in non-directed donation derives from the notion that the anonymous donor does not receive the direct emotional benefits as say, a parent donating to their child.

A recent report on donation for medicine and research defines altruism as an "ethical value", including it in a list of other values considered relevant; autonomy, dignity, justice, the maximising of health and welfare, reciprocity and social solidarity (Nuffield Council on Bioethics, 2011). Finally, a poll conducted in the UK in 2011 found that 8% of adults said they would consider donating a kidney to a stranger (compared with 74% who said that they would consider it for a family member) (Channel 4 News, 2011). If 8% of adults actually donated a kidney, there would be no waiting list for transplants.

This chapter begins with a definition of altruism as it is applied to kidney donation and a discussion of the way it is constructed in texts. Next, a review of existing research on living donation is presented. This will be followed by a discussion of the development of philosophical, psychological and psychoanalytic theories of altruism. Discourses of the body and organ donation will be explored, with the aim of describing the availability of various social ways of thinking and speaking about altruistic donation. Finally, the aims for the study and research questions are described.

In line with Parker (2005), the intention in this introduction is therefore to “examine how certain kinds of explanation function and how certain limits are set in place by those explanations” (p147). I understand these limits to mean the subject positions and possibilities for the subjective experience of “altruism” that are made available. I aim to draw attention to the way that the label “altruistic” has been adopted in the medical and lay literature. Inevitably though, through my adoption of the term ‘altruistic’, this research imposes a socially pre-determined framework on the participants’ and other texts in this study. Haraway (1991) argues that the invocation of a construct as an analytic device is inescapable.

D.2.1 Defining “altruism”

The aim of this study is to explore the social and psychological meanings that are constructed and available through language around a very specific form of behaviour that has been termed “altruistic kidney donation” (NHS, 2012). Other terms for this practice include “non-directed” or “stranger living kidney donation” (Nuffield Council on Bioethics, 2011). These terms describe instances of when an individual anonymously donates a kidney to the general pool of patients in need of a transplant. The Human Tissue Authority, the body responsible for meeting the legal requirements of the Human Tissue Act 2004, defines altruistic donation in the following way:

“Altruistic non-directed donation: A form of living donation whereby an organ (usually a kidney)...is donated by a healthy person who does not have a relationship with the recipient and is not informed who the recipient will be.” (Human Tissue Authority, 2011, p9)

Altruistic behaviour and motivation seem to be difficult concepts to grasp. At its most simple, altruism is defined as the motivation or desire to benefit another person (Batson, 2011). Cohen (1978) defines altruism as composed of three elements: "...giving or the desire to do so, empathy, and no motives of reward from the object of the altruistic behaviour" (p81). All three elements have to be present for genuine altruism to exist according to Cohen. For the purpose of the current study, this definition is considered to be sufficient and is consistent with constructions of living kidney donation in official and lay discourses.

The concept of altruism suggests a view of human nature that is sometimes distinctly at odds with the evidence before us, yet at other times seems entirely natural and obvious. Monroe (1996) suggests that in so much of contemporary life in the west self-interest is the norm. Philosophers, theologians and latterly, psychologists, have debated whether or not human individuals can be truly altruistic and the properties of ethical behaviour for thousands of years. Thomas Nagel (1970), in a detailed philosophical justification of "the possibility of altruism" concludes his argument in the following way:

"To say that altruism and morality are possible in virtue of something basic to human nature is not to say that men are basically good. Men are basically complicated; how good they are depends on whether certain conceptions and ways of thinking have achieved dominance, a dominance which is precarious in any case" (p146).

I take the position that the concepts of altruism in individuals and giving are inextricably bound up with social constructions, obligations and meaning (Mauss, 1954), and this study is therefore situated in a social constructionist framework, which will be discussed fully in the next chapter.

D.2.2 Constructions of "altruism" in text

When applied to kidney donation, the term 'altruistic' is used by the regulatory bodies in the UK for cases in which the donor does not know the recipient. The implication of the use of "altruistic" is that no benefit is experienced by the donor in the way that the directed, or related donor, is perceived to benefit emotionally through having given a loved one the "gift of life". I will argue that this absence of obvious emotional benefits is paradoxically also the reason that altruistic donors'

motives have been held to be potentially suspicious. In the literature, the principle of altruistic donation itself is lauded:

“Altruism receives its highest expression in the absence of personal relationships – ie. when there can be no question of even emotional self-interest. The gift of an organ to a complete stranger, whose identity is concealed from the donor and from whom the donor’s identity is concealed, seems worthy of the highest respect” (Evans, 1989, p19).

This statement is nevertheless ambivalent in its use of the word “seems”. The author is suggesting that there may be something else going on here. The use of the word “altruistic” in the social construction of kidney donors sets up the potential for confusion in the way in which these donors are positioned. Are they to be regarded as the apotheosis of human goodness or with scepticism as to their true motives? An alternative, less value-laden description is the “Living Anonymous Donor (LAD)”, which is sometimes used in the North American literature (eg: Landolt et al., 2001). However, “altruistic” is the term used by the official body with legal authority for transplants in the UK and is used in media reports and in patient literature. It is therefore used in the current study because it is the term that is available to participants when constructing their decision.

Altruistic kidney donation is constructed through discourse as a very specific form of ethical or moral behaviour. It seems to provoke a myriad of discursive responses from people, ranging from admiration to confusion, criticism, guilt and anxiety. In the academic literature, the altruistic donor’s “real” motives are sought. In contrast, media accounts construct altruistic donors as heroic, selfless individuals saving the lives of otherwise helpless individuals who face either death or the prospect of years of painful and intrusive treatment “hooked up” to a dialysis machine.

In the most up-to-date consideration of the ethics and social background to organ donation available, altruism as an ethical value remains the *recommended* basis for all blood and organ donation in the UK: *“...an altruistic basis for donation helps underpin a communal, and collective approach to the provision of bodily material for others’ needs, where generosity and compassion are valued”* (Nuffield Council on Bioethics, 2011, p132). The notion of organ donation as a “gift”, as compared with a financial arrangement, will be explored below.

In this study, I draw on Foucault's notion of genealogy in discourse analysis in terms of knowledge, power and materiality (Hook, 2001). To that end, I will review the theoretical literature on altruism and the research literature for living kidney donation with the aim of identifying the points at which the idea of altruism as psychopathology arises. Arribas-Ayllon & Walkerdine (2008) say that Foucauldian discourse analysis aims to draw on different forms of text so that discourses and relationships between them can be studied. This means that theoretical, research and official literature is considered to be a type of "expert" text in the current study. Discourses found in interviews with donors carried out for the current study, along with those in media reports will be compared with "expert" discourses.

D.2.3 Living kidney donor research

2.3.1 Assessment research

No qualitative research with altruistic kidney donors has been found, although there are anecdotal, first- and third-person accounts. Gohh, Morrissey, Madras & Monaco (2000) present a case study of a woman who successfully completed an altruistic donation in the authors' clinic, briefly describing the motivation of the donor, but this is not qualitative research and makes no claims to an analysis. Similarly, Hoyer (2003), a German surgeon, gives an account of his own experience of donating a kidney to a stranger and the considerable opposition he received from his peers, constructing his decision in terms of Christian tradition.

From a clinical and legal assessor's point of view, autonomy, informed consent and the lack of coercion are the key ethical issues for both directed and non-directed forms of donation and medico-legal discourses constitute the dominant discourses in the academic literature. In light of the paucity of existing empirical research on altruistic donation, this literature review will include research on directed kidney donation and other types of bodily donation where relevant. This approach is supported Adams et al. (2002), who suggest that altruistic donation shares many psychosocial features with the decision to donate a kidney to a relative or non-related person with whom the donor has a relationship such as a partner or friend.

In one of the earliest published papers on living, genetically unrelated kidney donors, a retrospective study with eighteen participants who had previously donated a kidney to an unrelated recipient, Sadler et al. (1971) suggest that

“these donors challenge us to respect human altruism and to consider its nature as a further groping toward self-integration” (p86). Altruism was constructed at that time as incompatible with the behaviourist theories that dominated psychology. However, this statement contains the important suggestion that altruistic donation might be thought of as an adaptive mechanism linked to psychological change. The authors base this conclusion in the overwhelmingly positive retrospective evaluations given by the donors to their experience.

In addition to a finding of positive outcomes for donors, the most striking aspect of Sadler et al.’s (1971) paper is to be found in the discourse of profound distrust towards non-related donors that was expressed by medical professionals surveyed, some of whom are reported as viewing donors as “impulsive, suspect and repugnant” (p99). At the time this study was conducted, before the development of modern immuno-suppressants, the use of live, unrelated donors was still considered to be an experimental, rather than a therapeutic treatment, in which many recipients died after transplant. Doctors and surgeons would no longer dream of describing their patients as “impulsive, suspect and repugnant”, yet to what extent is an attitude of mistrust repressed by the use of these prevailing discourses of altruism? Massey et al. (2010) found that people in the immediate social environment of altruistic donors are more likely to react with scepticism to the donor than those in the general public.

Since altruistic kidney donation is a relatively new clinical procedure and still rare in comparison with directed donation, much of the literature consists of descriptions of how transplant clinics have developed their assessment procedures for altruistic donors. Altruistic donation is problematized in these articles, constructed as something like a medical condition itself, to be clinically managed and monitored for outcomes. Assessment protocols have generally evolved from the procedures used for assessing directed donors. Adams et al. (2002) and Jacobs et al. (2004) are examples of this type of article, and describe, in varying degrees of detail, psychological assessment and contra-indications to altruistic donation. The overall aim of these assessments is to establish capacity, obtain informed consent and avoid negative psychosocial outcomes for donors.

Adams et al. (2002) review the findings on assessment of altruistic donors and conclude that “socially acceptable” motives for non-directed donation to be found in the literature are; altruism, religious beliefs, a desire to reciprocate to society

and a desire to honour an individual who died waiting for a transplant. Adams et al. (2002) point out that there is no comprehensive understanding yet for the psychological and emotional impact and motivation for altruistic donation. Rodrigue et al. (2007) support this view and suggest that agreement on the scope of assessments of anonymous donors is currently limited because of a lack of data on psychosocial outcomes.

In a response to the expansion of the practice of altruistic donation in the US, an article by Dew et al. (2007) recommends that guidelines for psychosocial evaluation of altruistic donors should be based on clinical consensus and the principle that the donor is considered to be a patient with the same status as the potential recipient and is owed the same duty of care. The authors suggest that the following factors will protect the donor from a poor psychosocial outcome; the absence of psychopathology in the present or recent past, no substance abuse/dependence, a knowledge of the risks and benefits for donor and recipient, little or no ambivalence, realistic expectations about outcome, a history of medical altruism, a history of reasonable adaptation to life stressors, and support from the family for donation. Jacobs et al. (2004) argue that most contra-indications to altruistic donation are the same as for directed donors, including active grief or severe depression.

Discourses of the possibility of donor self-interest runs implicitly throughout journal articles about living kidney donation but is rarely referred to directly. Lurking beneath these discourses of “psychosocial” assessment is the spectre of the donor whose motivation for giving is “wrong”, and not genuinely “altruistic” but instead may signal the possibility of mental illness or personality disorder. This possibility is addressed through the literature’s overwhelming focus on the need for clinicians to rule out the possibility of psychological disorders.

Psychopathology measures are cited and references are made to DSM Axis I and II criteria (eg. Jendrisak et al., 2006).

Kranenburg et al. (2008) carried out a careful systematic review of this concise clinical literature on altruistic donation and found that although there are similarities in approach, with five articles describing an interview and psychometric testing, there is no agreement on the best measures or assessment protocols to use. In the literature, “altruistic” donors are positioned as something of a psychological oddity, suspected as being at risk of psychopathology and needing

to be assessed in order to establish their mental health. The functions of these discourses are benign in intention and ethical in respect of medicine's first principle not to harm. Authors, who are usually clinicians, want to ensure that the donor is protected from the risk of harm, or from implicit coercion by others. However, one unintended consequence of these discourses of psychopathology is the suppression of discourses of the morality and ethics of organ donation itself, about what else may be going on in "altruistic" donation. This task is left to medical anthropologists and sociologists and will be reviewed later in this chapter.

2.3.2 Outcome research

A positive outcome in terms of self-esteem is found throughout the directed donation literature. This is a particularly strong finding in Fellner & Marshall (1968). Although Adams et al. (2002) point out that it is not known whether the psychosocial outcomes for directed donors are the same as for non-directed donors, there is some evidence for a similar good outcome. Findings are limited however; Jendrisak et al. (2006) followed up seven non-directed donors at three months after transplant and found that they all had positive psychosocial outcomes, "a high degree of self-satisfaction" (p119) although no further follow-up was made. Increased self-esteem has also been found in a more recent outcome study of 24 altruistic donors in the Netherlands (who had been carefully screened before donating for psycho-social risk factors), in which 75% of participants said that they had donated because they wanted "to help someone" as their main reason (Massey et al., 2010).

Massey et al. (2010) wanted to explore whether there was any justification for the assumption of the risk of psychopathology in 24 altruistic donors, interviewed two years after donating. They found that donors reported major positive psychological effects and only limited negative impact and this was in spite of the fact that nearly half of these donors had a history of psychiatric diagnosis before donating. Massey et al. (2010) suggest that the less than positive outcomes reported in the minority of donors in their study might be linked with their experience of scepticism and lack of understanding from people in the altruistic donor's environment, saying; "the attitude of those in the donor's social environment appears to more closely mirror the scepticism toward this type of donor within the transplant community [than that found in the general public]" (p1451). This is an important finding because the altruistic donor literature, limited though it is, has tended to

assume that the mental health and wellbeing of the altruistic donor is more likely to be at risk when compared to directed donors, who have access to more obvious and socially available emotional gains (Massey et al., 2010).

Dew et al. (2007) suggest a list of characteristics that they consider to be factors that are likely to contribute to poor psychosocial outcome following altruistic donation. These are; significant psychiatric disorders, either past or on-going, substance abuse/dependence, limited ability to understand risks and benefits for both donor and recipient, ambivalent or unrealistic expectations, motivation that reflects a desire for recognition or a personal relationship of some sort, family stressors or obligations, expectation of secondary gain and a poor relationship with family or a family that does not support donation.

2.3.3. *Donor motivation studies*

Studies of directed donors present subtle differences in discourses. In a phenomenological study of twelve prospected related donors, Lennerling, Forsberg & Nyberg (2003) divided motives for donating into seven categories: A 'natural' desire to help; the expectation of increased self-esteem from doing something good; identifying with the recipient; the benefit to the self and quality of life through the recipient's improved health; logic (no reason not to); external pressure and a feeling of moral duty that cannot be questioned. These authors concluded that the decision was based mainly on emotions and practical information from medical professionals contributed little to the process (Lennerling et al., 2003).

In contrast, for "altruistic" donation to a stranger, the idea that the donor might be motivated purely by emotion is apparently met with some suspicion. Edwards (2001) points out that the concept of emotions can be used rhetorically either in contradiction with, or in support of cognitive processes. In the studies outlined above, the former rhetorical construction, emotion *versus* cognition, is implicit and underlies the analysis of the instantaneous, voluntary decision to donate given by Gill & Lowes (2008). The absence of a relationship between the altruistic donor and the recipient appears to make it hard to account for within current socio-cultural discourses (Lamanna, 1997; Roff, 2007). Roff (2007) reviews the altruistic donor literature and the ethical implications of regulating altruistic donation, concluding that throughout the 20th century, the dominant moral philosophy has

positioned altruism as incompatible with rationality. Rationality has been constructed in terms of self-interest and moral emotions entirely disregarded, and this is the reason that altruistic donors have been traditionally met with suspicion (Roff, 2007). Roff (2007) suggests that the answer may lie in a “new moral economy” that is able to incorporate altruistic donation and recognise its generosity (p441).

Jacobs et al. (2004) include a section on some of the motivating factors of 49 prospective altruistic donors. These include a utilitarian argument for putting a “spare” kidney to use; wanting to help without any expectation of personal gain; a way of practicing a Christian faith and as a way of “grieving effectively” after someone close to the donor had died (Jacobs et al., 2004, p1112). The authors do not provide any details of an analytic strategy or methodological approach to the data however so it is not clear how these themes were arrived at.

Henderson et al. (2003) used a prospective, hypothetical design to assess 93 individuals who autonomously approached the authors’ transplant centre in Canada offering to donate to a stranger. They employed a series of mental health measures and a clinical interview that they adapted from a validated adult attachment interview. Henderson et al. (2003) found that “suitable” donors were more likely to express a desire to make a substantial improvement in another person’s life with an acceptable level of personal cost, had a consistent spiritual belief system and previous experience of transplantation or medicine. They were also more likely than a control group to be considered to be altruistic by objective standards, so were more likely to have been blood donors, community volunteers and/or be registered bone marrow donors. Henderson et al. (2003) suggest that contrary to assumptions, altruism expressed through kidney donation can be consistent with psychological health. However, the hypothetical design of this study means that the individuals who agree that altruistic donation is a good thing *in principle* may not be the same individuals who are prepared to go ahead with an altruistic donation.

Landolt et al. (2003) also surveyed peoples’ hypothetical willingness to be altruistic donors and found that 29% of 500 people contacted said that they would be willing (in principle) to be altruistic donors. Again, there is a limitation with this finding as there is no way of assuming that these results would apply to actual donors. There is support from Jacobs et al. (2004), in their account of the

motivations of 49 actual altruistic donors at their clinic but as discussed above, these accounts appear to be largely anecdotal rather than empirically derived.

2.3.4. Qualitative research with directed kidney donors

There is some qualitative research with related or directed kidney donors. Belle-Brown et al. (2008) employed a phenomenological approach to explore the experience of 12 directed donors and found that three key themes emerged in the decision making process. These were the experience of a loved one's illness and suffering; intra-personal and social factors, and the powerful emotions associated with the opportunity to give someone life (Belle-Brown et al., 2008).

An instantaneous, overwhelmingly positive response by donors when they learn of the possibility of donating has been highlighted in the literature since the earliest studies. Fellner & Marshall (1968) were struck by the fact that the majority of participants in their study with twelve directed donors (mothers and siblings of the recipients) reported that they made a decision to go ahead with the donation immediately they were asked, before they had had the opportunity to consider the implications of what they were agreeing to. Fellner & Marshall (1968) describe this mode of decision making as "irrational" (p2703) and not in line with the notion of informed consent, which would have been a "rational" decision. Donors in this study reported that they were not particularly interested in the information given by medical professionals, choosing instead to "trust" the doctor's expertise and benign intentions (Fellner & Marshall, 1968).

Gill & Lowes' (2008) longitudinal phenomenological study of related donors found that donors reported that their decisions to donate were made voluntarily and instantaneously, without a period of reflection. This was the case even for those relatives who agreed to donate but later said that they had privately hoped that they would be found to be immunologically compatible. The speed of decision is assumed in the literature to mean that it is based not on cognition, but on emotions. Lennerling et al. (2003) also concluded that the twelve perspective donors in their phenomenological study based their decision to donate mainly on "emotions" and that there was little influence on the decision-making process by medical and practical information. Motives to donate were divided into seven phenomenological categories; a 'natural' desire to help; increased self-esteem from doing something 'good'; identifying with the recipient; benefit to the self and

own quality of life through the improved health of a partner/spouse; external pressure (from a doctor) and a feeling of 'moral duty' that cannot be questioned (Lennerling et al., 2003).

In a qualitative study of living liver donors' decision making process, Papachristou, Marc, Frommer, Burghard & Klapp (2010) also report being struck by the initial speed with which all twenty-eight donors participating in a qualitative study apparently came to a decision, before they had been given sufficient information to make it informed, and suggest that this indicates decision-making based on an emotional rather than a logical process. The two modes of decision-making, logical and rational versus emotional and irrational are therefore implicitly positioned in the literature in opposition to each other. Papachristou et al. (2010) suggest that four groups of attitudes were to be found the interviews; heroic, fatalistic yet optimistic; optimistic yet apprehensive; informed and realistic and uncertain/anxious.

Franklin & Crombie (2003) give a qualitative account of parents' and siblings' decisions to donate a kidney to family members but avoid the imposition of a rational versus irrational framework. The instantaneous decision made by donors is again highlighted in this study, as well as the donors' experience of increased self-esteem after donating. Interestingly for future research, although beyond the scope of the current study, Franklin & Crombie (2003) included interviews with recipients of donated organs, highlighting the complex relationships and not always positive relationships that can ensue when the recipient experiences a sense of obligation to their donor. Combining two studies with different but compatible methodological approaches; a psychological study, using content analysis in a phenomenological framework, and an ethnographic one, the authors argue that living organ donation is best understood in the context of both the psychological and the socio-cultural domains (Franklin & Crombie, 2003).

Franklin & Crombie (2003) found that although no donors expressed regret for their decision and all described increased self-esteem afterwards, the decision to donate was more problematical for siblings than for parents, and harder for fathers than mothers, which in some cases led to psychological distress. Some siblings expressed regret that the decision had not really been theirs at all, suggesting that implicit coercion meant that they were not able to refuse. A particular strength of this study was the large number of participants interviewed.

D.2.4. Theories of altruism and gift giving

2.4.1. Psychological theories of altruism

In 1970, Darley & Latané noted; “altruism presents a problem for psychology” (p83). According to the behaviourist perspective dominant in psychology at that time the argument was made that human individuals always act on the basis of positive or negative reinforcement. Altruism could only therefore be explained by the benefits it afforded the altruistic individual, for instance in terms of a boost to self-esteem, or through the reduction of personal distress. Wispé (1978) describes the possibility of a sense of moral superiority that an individual feels when they exceed “moral norms” (p2), which is consistent with a theory of drive reduction. This led to a “hedonistic paradox” being posited in which helping behaviour was argued from a psychological perspective to be aimed at self-reward and therefore never truly altruistic. Early social psychology studies of altruism and helping behaviour included Latané & Darley’s (1970) classic bystander research into the situational determinants of helping behaviour, as well as naturalistic reports of self-sacrifice (eg. London, 1970). As Monroe (1996) argues, this research was situated in “the assumption that self-interest is an intrinsic part of human nature” (p3).

At the same time, biological approaches favoured a genetic explanation of altruism. Wilson (1978), an evolutionary biologist, argues that altruism can be selected for in a population as long as the beneficiaries of the altruistic behaviour also carry some altruistic genes and the benefits enable that beneficiary to multiply those genes. Wilson argues that “reciprocal altruism” (Trivers, 1971, cited in Wilson, 1978) confers genetic fitness on a society. This approach proposes that altruistic or “good Samaritan” behaviour is rewarded by the possibility of reciprocal helping in the future, thus increasing both individuals’ chances of survival. Biological psychology explains the evolution of systems of morality in this way and suggests that successful social living requires that biologically driven tendencies for selfish survival are over-ruled.

Campbell (1978) provides an example of how a “social indoctrination” of self-sacrifice can cause human beings to over-ride their own instinct for survival, citing the willingness of individuals to die in a war. It is the reason, Campbell (1978) suggests, that all the major world religions emphasise the dangers of sin and immorality and in doing so “...represent social evolutionary products directed at

inculcating tendencies that are in direct opposition to the 'temptations' representing for the most part, the dispositional tendencies produced by biological evolution" (p52). "Indoctrinability", or group identification, may therefore provide a sufficiently adaptive advantage to outweigh the adverse effects on genetic selection for self-sacrificing altruism (Campbell, 1978, p53).

Cohen (1978) also describes how religions stress the value of empathy or sympathy as a desirable human quality, and argues that this is a tradition rather than a "psychological reality" (p95), arguing instead that empathy, the emotion that has been most often used to define altruism is prevalent in many human cultures, notably western ones. Although at a group or social level, altruism has a clear adaptive function, allowing hunter-gatherer societies to survive by sharing resources when necessary, at the individual level it is not at all clear from the study of other cultures that altruism is an innate human characteristic argues Cohen (1978), who suggests that empathy and individual altruism is in fact culturally dependent. Giving is a socio-cultural act, not a psychological fact and as a result, tension exists between hedonistic individual drives and socio-cultural expectations of helping, in which the notion of overcoming personal drive is constructed as a desirable aim, one that is considered to confer a "capacity for greatness" on individuals (Cohen, 1978, p97). In this way, altruism and morality can be explained as a product of social, as opposed to biological evolution, and the desire to help others is socially inculcated.

The most current social psychological research on altruism posits that it is a motivational state and is related to our tendency to nurture our children (Batson, 2011). In this everyday nurturing, central to the human experience, we can find evidence and explanations for altruism and Batson (2011) proposes that altruistic motivation is produced by "empathic concern", which he defines as: "...other-oriented emotion elicited by and congruent with the perceived welfare of someone in need" (p11). This concept of empathic concern incorporates many emotions, including "sympathy, compassion, softheartedness, tenderness, sorrow, sadness, upset, distress, concern and grief" directed towards another person (Batson, 2011, p11). According to this definition and understanding of empathic concern, it must be "other-oriented" to be linked to altruistic motivation and is defined as a "motivational state with the ultimate goal of increasing another's welfare", which is contrasted with egoism, "a motivational state with the ultimate goal of increasing one's own welfare" (Batson, 2011, p20). Both motives, altruistic, and egoistic, can

exist simultaneously in an individual, and there will only be conflict if the behaviour to which the two motivations lead are different (Batson, 2011).

Batson (2011) asserts that “a person may be altruistically motivated and not know it, may be egoistically motivated and not know it, may believe that his or her motivation is altruistic when it is actually egoistic, and vice versa” (p22). According to Batson’s approach to motivational stages; “Self reports cannot be trusted to reveal a person’s motives, especially such value-laden motives as those for benefitting another (2011, p23).” It is not necessary for altruism to involve self-sacrifice and this concept of altruistic motivation can withstand a “weak form” of the problem of “psychological hedonism” because although goal attainment is likely to bring pleasure to an individual, this benefit to the self is secondary to the primary goal, which is to benefit another person rather than the self (Batson, 2011, p22).

This approach to altruism is supported by attachment researchers Mikulincer et al. (2005), who link attachment security to altruistic helping and caregiving, suggesting that attachment insecurity interferes with the tendency to empathically respond to distress in others. Attachment avoidant individuals are not comfortable in the presence of other people’s need because of the closeness and interdependence this demands (although avoidant people may view helping others as a route to enhancing fragile self-esteem), anxiously attached individuals find their own distress in response to the needs of another prevents them from being effective caregivers, whereas secure attachment status enables a shift in perspective from the needs of the self to the needs of others (Mikulincer et al., 2005). Mikulincer et al. (2005) claim that their studies also show that secure status does not have to be dispositional, but by enhancing an individual’s experience of security in attachment, care-giving ability can be enhanced.

2.4.2 Gift exchange theory

The majority of research into motivating factors in kidney donation has focused on donors who have a relationship with a prospective recipient, either of kin, marriage or friendship, which is known as directed donation. This type of donation has been theorised in terms of Mauss’ (1954) gift exchange theory, in which gifts are a way of creating and maintaining social networks. Titmuss (1970) applied gift exchange theory to the human body in an influential study on blood donation. The powerful nature of the “moral enforcement” of any gift exchange in a social group is

highlighted by Titmuss (1970), who regards voluntary anonymous donation of blood as free from a “situation of power, domination, constraint or compulsion, no sense of shame or guilt, no gratitude imperative, no need for penitence...or wish for a reward or a return gift” (p89). Titmuss (1970) concludes that an altruistic basis to donation is necessary for the benefit of society and that social gifts and actions enable the realization of the self because they allow an expression of the need to help. Discourses of organ donation as a gift have been in use ever since and this approach to donations involving the human body is still dominant in the UK (eg. Nuffield Council on Bioethics, 2011).

Schwartz (1967) drawing on psychoanalytic relational ideas, describes the social psychology of gift giving and receiving in terms of the imposition of, followed by either acceptance or rejection of identity, and argues that it gives insight into “the idea which the recipient evokes in the imagination of the giver” (p2). The idea that we define ourselves through what we give to others, in other words in relationship with others, is consistent with a psychoanalytic understanding of how the ego or self forms inter-subjectively, in conscious and unconscious relation to real and imagined objects. Schwartz (1967) adds that being able to give gifts leads to reward in the form of an image of the self as “a source of gratification to others” (p3). The possibility of an association between gift giving with guilt and self-sacrifice is also suggested (Schwartz, 1967).

Gift exchange theory discourse is therefore useful in a general discussion of organ donation because it can function to provide a way to avoid asking difficult questions about altruism, providing an alternative theoretical framework for understanding. As Lock (2002b) suggests, human organs have a “social life” (p315), but theorising the social life of organs in terms of gift theory seems not to work as well when living donation to a stranger is considered. Lamanna (1997) suggests that this is because a gift needs to be seen by society as appropriate to the magnitude of the relationship between two people. The “altruistic”, anonymous “gift” of a kidney, involving as it does a “major violation” of the body, can lead to a situation in which “a person whose gift is out of line with social obligation has called his/her normality and social integrity into suspicion” (Lamanna, 1997, p171). In this way, altruism makes people uncomfortable, perhaps because as Lamanna (1997) argues; “Suspensions voiced about altruism may represent a concern that if altruism is seen to be within the normal human repertoire, social norms will then

mandate sacrifices for others deemed inappropriate in our culture...altruism as a normal expectation" (p175).

The dark side of gift giving has been applied in the context of organ donation by anthropologist Nancy Scheper-Hughes (2007), in a fierce criticism of the use of living organ donors whom she describes as compelled to give in an act of "sacrificial violence" (p507). She questions the ethical implications of the fact that it is frequently women who are compelled to be the donors in families in an extension of their 'caring' role, and the shift within recent decades in the US of donated organs being given by the young to their elderly relatives, which she links to the development of a highly individualistic society. That she does this in the *American Journal of Transplantation* can be read as immensely provocative and her argument *against* honouring living donors is one of the few and certainly the clearest counter discourses to altruism to be found anywhere in the literature.

2.4.3 Philosophical explanations of altruism

Hedonistic explanations for altruism in psychology reflect a Kantian perspective. In the 18th century, Kant argued that emotions, including altruistic emotions, as distinct from reason, are irrational and unreliable, therefore not governed by morality. Accordingly, emotions are not useful for generating either knowledge or moral judgement so altruism is considered to be essentially egoistic in motivation (Blum 1980). Morality, according to Kant, must be universalizable, derived from rational (un-emotional) process and impartial to the interests of individuals. Any process that can be argued to have self-interest as a motivating factor is therefore against morality: "To be moral is to respect others as having equal value to oneself, and as having an equal right to pursue their own interests" (Blum, 1980, p3). Furthermore, the Kantian view of morality contains obligation at its heart, that is, we are obligated to perform moral actions (Blum, 1980).

According to Blum (1980), this Kantian moral tradition is deeply ingrained in contemporary Anglo-American moral thinking and experience. I agree that a Kantian approach is evident in the ethical and legal framework that governs medicine and organ donation, ensuring that a system of assessment is in place to assess and account for any possible "irrational" motivation that may arise from mood or emotion disorders in donors. This is not to say that the emotional

component of altruism is not recognised, it is, but it must be contained within the contemporary understanding and boundaries of “rationality” or “sanity”.

Against the Kantian, egoistic conceptualisation of altruism, Thomas Nagel sets out a detailed justification for the possibility of the existence of rational, genuine, “pure” altruism (1970). “Pure altruism” can be proven to exist in individuals, Nagel (1970) argues, describing it as “the direct influence of one person’s interest on the actions of another, simply because in itself the interest of the former provides the latter with a reason to act” (p80). For Nagel (1970), altruism constitutes a rational requirement for action because it can be proved to be the expression of “objective, rather than subjective values” (p88) (although he does not dispute the existence of the subjective experience of the individual, he maintains that it is not required for altruism to occur). For objective (rational) values to exist, they require simply that there is “full recognition of the reality of other persons” (Nagel, 1970, p88). The interest of others alone can motivate an individual to act so Nagel (1970) argues that we therefore always have available a rational (ie. not egoistic or grounded in emotion) reason to act altruistically.

For Blum (1980) the possibility of pure altruism can coexist with altruistic emotions, although he recognises that some feelings, such as guilt for example, if they constitute the motivating factor, may mean that helping another person is in fact “pseudo-altruism” (p123). Blum (1980) argues that the “crucial moral distinction” in assessing whether an act is or is not altruistic is not whether emotion or pure reason is the motivating factor but whether it is out of concern for the good of the self or concern for the good of another person (p124). Blum’s (1980) critique of Kantian morality and consequent support for the moral basis of altruistic emotions fits well with the relational ontology of Counselling Psychology because it incorporates an “engagement with and reorientation of our emotions, and, more generally of our being-towards-others” in a pluralistic view (p7). Blum (1980) calls this “ordinary moral consciousness” (p7). Put simply, it is the proposition that it is good to care about other human beings.

The idea of “direct altruism” is therefore in conflict with the Kantian view described above. It is an understanding of altruism that “draws on an intuition which...has played a fundamental role in demarcating the domain of the moral at least since the advent of Christianity” (Blum, 1980, p85). This is one way of accounting for the tension apparent in a contemporary understanding of altruistic organ donation

between the Kantian argument that emotions are irrational and therefore must not be incorporated in moral decision-making, and the social and religious principle of the fundamental morality of helping people in need.

2.4.4 Psychoanalytic understanding of altruism

A pathological association between altruism and masochism is attributed to Anna Freud (1936). Freud's is a pessimistic view of altruism that is pervasive and remains current in some psychoanalytic (and psychiatric) thinking (Seelig & Rosof, 2001). Altruistic behaviour in analytic patients is described using this discourse in terms of "altruistic surrender", in which the interests of a proxy are energetically promoted because a severe superego is unable to permit the gratification of instinctual desires (A. Freud, 1936/1966, p123). The wishes and desires of the individual are projected into the proxy and the altruistic individual is able to gain satisfaction through identification.

Ekstein (1978) describes how psychoanalysis has traditionally viewed altruism as a defensive symptom of intra-psychic conflict that takes the form of a reaction-formation to greedy or sadistic impulses. Seelig & Rosof (2001) state that in psychoanalytic terms; "...altruism has been generally regarded by most analysts as predominantly a conflict-laden compromise formation...a subcategory of masochism" (p937). Meissner (2003) is dismissive of this approach however, saying; "Interpretations reducing altruistic behaviour to egoistic motives – common in analysis - are no more than ad hoc hypotheses lacking adequate evidence" (p163).

Seelig & Rosof (2001) describe from a clinical psychoanalytic perspective five categories of altruism, distinguishing between "normal and pathological altruism" whilst acknowledging that there are potential ethical, political, cultural and philosophical problems inherent in such a categorisation. Seelig & Rosof (2001) suggest that altruistic behaviour is pathological when it is maladaptive for the individual, comparing this with "normal" altruism, which increases self-esteem and is therefore healthy. Type I, "proto-altruism", is the species-preserving instinct present in animals and humans (p934). Seelig & Rosof (2001) explain its origins in terms of a benign projective identification of proto-altruism by the mother to the infant. This is consistent with Shapiro & Gabbard (1994), who argue that altruism is partly a result of object relations and attachment patterns internalised in infancy

and childhood in which early interaction combined with genetic factors will determine whether an individual is predominantly narcissistic, altruistic, or a combination of both.

Type II, “generative altruism”, develops out of “proto-altruism” and is characterised as the adaptive ability in individuals to enjoy the success or pleasure of another individual in a conflict-free way as a function of an autonomous ego. This type is associated with psychological health and the example of a parent enabling their child to achieve its goals is given. This is similar to Erikson’s (1964) idea of generativity, which he considered to be a positive goal of mature adulthood in his lifespan development theory. Contrary to Erikson (1964) though, Seelig & Rosof (2001) consider that pure generative altruism is likely to be rare.

Type III is a conflicted version of altruism, which may have “pathologic elements” (p947), such as when a parent experiences the need for a child to achieve the parent’s goals and the child is drawn into a type of altruistic behaviour that is conflicted because they are concerned with satisfying the parent. It is not entirely clear whether the parent, or the child is the conflicted altruist, or perhaps both. This type, although defensive in origin, can be adaptive in its effects.

Type IV is described as “pseudo-altruism”, and is held to be a maladaptive defence against underlying sadomasochism involving “...efforts to defend against profound aggression, envy, and a superego-driven need to suffer and be a victim” (Seelig & Rosof, 2001, p934). Its narcissistic pathology restricts the individual’s ability to obtain direct gratification, instead compulsively defending against aggression and envy by making sacrifices and taking care of other people. There is no genuine pleasure in the success of the proxy. Seelig & Rosof (2001) suggest that this type of altruism is often associated with depression in clinical patients. The final type V is “psychotic altruism” (p934) in which the individual is delusional and driven to damage or sacrifice themselves for the welfare of others.

In an argument for a ‘non-defensive’ view of altruism, Shapiro & Gabbard (1994) present an argument in favour of the adaptive function of both self-interested and other-interested behaviour in humans, drawing on evolutionary theory, ethology, infant research, experimental psychology and object relations, and suggest that “the optimal balance of both [self-interest and other-interest] underlies mental health” (p25). They do not rule out the possibility for self-interest being met whilst

acting predominantly in the interests of another; "...a positive emotional reaction following a self-sacrificing act is not in itself incompatible with altruistic behaviour" (p32). Meissner (2003) too argues that "healthy narcissism and... mature forms of object love" will increase the capacity of an individual for altruism (p175). Shapiro & Gabbard (1994) conclude their argument by making a case for the central role of altruism in the psychotherapeutic relationship, focusing on the therapist's struggle to negotiate a balance between their own narcissistic and altruistic tendencies in the service of the client.

D.2.5. Discourses of the body

The Human Tissue Act 2004, which governs organ transplantation in the UK, was written to replace previous law after it was revealed that body parts and organs from children who had died had been kept by a hospital without the permission or knowledge of their parents with much resulting public and private anguish (Hope, Saveluscu & Hendrick, 2008). The public reaction to these events suggests that as individuals and a society, we have strong and very particular beliefs and feelings about the sanctity of the physical body; that to have parts taken away and kept without permission, particularly from children, is unacceptable to most people. As a result, the Act was written to govern how tissue and organs from living and dead patients can be removed, stored and used, with consent as its fundamental principle. The belief that our bodies are an intrinsic part of our selves does not, it seems, disappear with the death of that body.

2.5.1. Medicine, health and illness

For Foucault, the body is produced by, and exists in discourse. Discourse constitutes both the social and the psychological (Parker, 2005; Wetherell, 2008; Willig, 2008). Contemporary discourses in technology and medicine, those that apply to death, dying and the interface between bodies and machines, the notion of the 'cyborg' (Haraway, 1991), the sanctity or otherwise of our physical bodies, all these and others contribute to the availability of discourses for the construction of altruistic kidney donation. Writing from a feminist perspective on how biomedical discourses of the immune system in a post-AIDS world are used to construct the body, Haraway (1991) describes how contemporary human bodies have become more like "cyborgs" – cybernetic organisms – "compounds of hybrid techno-organic embodiment and textuality" (p212). Kidney patients attached to

dialysis machines, blood flowing between their body and the machine; surgeons transplanting organs from one living body to another; Haraway's (1991) discourses of the cyborg seem relevant to organ donation. The cyborg has wide cultural significance in Western imagination, ranging from Shelley's Frankenstein to the "bionic" men and women of the twentieth century, according to Howson (2004), who argues that although enhancement of the human body now occurs at every level of life in the west, it nevertheless still has the apparent power to provoke anxiety, calling into question what we think of as 'natural', inducing "boundary paranoia" (p90). Such boundary anxieties about the melding of human and artificial or alien life are reflected in films such as Alien, Robocop and Terminator. Boundary anxieties also surface when new medical technologies in reproductive techniques, organ transplantation or biotechnology are considered, according to Howson (2004). Biotechnological advances force us to confront what we mean when we think about what it means to be human and the limited extent to which we seem to be able to tolerate being mixed up with other living things or machines.

In a recently written forward to his classic 1970's essay on medicine's power to change our understanding of health and illness, Illich identifies how modern medical techniques have the symbolic power to "shape our basic certainties", promising the possibility of "technologically engineered happiness" that abolishes the need for suffering itself (2010, p. ii). According to Illich's argument, the person is transformed by medical discourses of function and feedback into a system, and in this process becomes to a certain extent disembodied. At some point in this medical revolution, a discursive distinction arose between "suffering"; the notion of "bearing with your flesh", and "coping", which is about "managing emotions, perceptions and states of the self conceived as a system" (Illich, 2010, p. vi). Sanner (2001) also argues that the machine metaphor that is prevalent in medicine and is so productive in terms of diagnosis and treatment, profoundly influences the way that bodies are conceived of.

Psychology has relatively little to say about the symbolic and cultural meanings of the body, the self and relationships to whole and parts. For an analysis of the discourses around organs and transplant surgery, the disciplines of medical anthropology and sociology are more productive. In some non-western cultures, Scheper-Hughes & Lock (1987) argue that a holistic, "mindful body" epistemology connects the bodies of individuals to the societies in which they live as well as to

the physical world. This relationship between the individual and the social entity has been largely absent from the discourses of modern western thinking. There have been pathological consequences of this estrangement, according to Scheper-Hughes & Lock (1987), with the loss of a sense of wholeness and bodily integrity seen in the way that “illness somatization has become a dominant metaphor for expressing individual and social complaint”, leading to modern psychosocial diseases such as eating disorders and addictions, or symptoms such as chronic pain for which no medical explanation can be found (p27). In Scheper-Hughes’ (2000) essay; “The Global Traffic in Human Organs”, she compares how the “transplant rhetoric of gifts, altruism, scarcities and needs” functions as a smokescreen for a much more sinister reality that exists for the world’s poor, who supply the organs for the rich (p192). In response, Alter (2000) describes how a modern culture of biomedicine has resulted in the “fetishization” of the living body as a collection of parts and a re-conceptualising of our relationship to illness and death:

“...organ transplantation is the radical instantiation of biomedicine’s underlying ontological assumption about the body’s natural state of health. On the assumption that an absence of sickness denotes natural good health, recovery is imperative and always possible. Biomedicine cannot accommodate death, hence the search for ever more radical modes of recovery, more technologically sophisticated means of extending life indefinitely, and also, I think, the search for more radical ways to “harvest” body parts, some of them from the same bodies whose life is extended. Although transplant surgery literally fragments the body, it is a process of fragmentation that is epistemologically linked not just to all surgery but to the fact that biomedicine reifies body parts—organs, blood, cells, chromosomes, and genes, for example - in its fetishization of life” (p 211).

Since bodies have been medicalized, discourses of the body have changed. Prior to the modern practice of anatomy, learned through dissection of cadavers, the body’s internal organs were considered to be the possession of the individual, whose integrity had to be maintained in death for resurrection (Lock, 2002a). The practices of medicine have led to the notion of organs as commodities, no longer the inalienable possession of the individual or their family, but as the rightful property of society or state. Lock (1995) argues that the ability to transplant

organs means that dichotomies that were previously considered to exist between nature and culture, and self and other are now subject to manipulation. Death is no longer “natural” but something to be rejected, and self and other can be mixed together in a justifiable effort to prevent it (Lock, 1995). Once viewed as in-exchangeable, organs are now constructed as “parts” that can be taken from one person and given to another, in order to prolong the life of the latter. Transplant surgery relies on the “harvesting” and “procurement” of organs, economic discourses that provide constructions of relationships between the person and the body, between bodies and their parts, and between people’s bodies to each other (Scheper-Hughes, 2000). And yet, as Lock (2002b) suggests, there exists a tension between emotional and rational discourses around organ donation;

“...mixed metaphors associated with human organs encourage confusion about their worth. On the one hand, the language of medicine insists that human body parts are material entities, devoid of identity whether located in donors or recipients. However, in the rhetoric promoting donation, organs are animated with a life force...”
(p319).

In these discourses, it is the person who is lost, or perhaps ignored for the sake of convenience. In Kazuo Ishiguro’s (2005) novel *Never Let Me Go*, the grisly fate of children who have been cloned for the sole purpose of supplying body organs is gradually and chillingly revealed. The lives of these fictional donors are given meaning only through their function, which is to save the lives of other, presumably more valuable, human beings. For the imagined society in which they have been created, they themselves have no intrinsic value beyond what their bodies can be used for. This story forces us to confront what it means to be human, because Ishiguro’s donor children are positioned as sub-human, their minds, souls, selves; whatever it is that we want to call the *person*, are worthless, to be thrown away like husks or shells as soon as their useful body parts are used up, or when they have “completed”, in Ishiguro’s haunting phrase.

2.5.2. Saving lives

Margaret Lock (2002b), in her book *Twice Dead: Organ Transplants and the Reinvention of Death* describes how a study in a medical journal reports a case of a brain-dead pregnant woman “kept alive” by doctors until the foetus is mature enough to survive outside its mother’s body. According to Lock (2002b) in this account of the technological accomplishment, alternative accounts are suppressed by this prevailing discourse:

“The chronic ambiguity created by keeping a living cadaver suspended in a hybrid state for over two months is suppressed in favor of a discussion about how the feat was accomplished and whether it should be routinized because the technology is available” (p166).

Following the question that Lock (2002b) asks in response to the case she describes, it is interesting to ask whether certain discourses about the social repercussions of living organ donation are being avoided or suppressed through prevailing discourses of altruistic donation? Scheper-Hughes (2000) argues that the concept of what constitutes life and death itself in the western world has been changed in the west by transplant surgery’s reliance on the category of “brain death”, and that ordinary people are no longer granted the expertise to determine what death is. Lock (2002b) explores how in Japanese society, instating a medico-legal concept of brain death has been immensely problematical, reflecting different cultural beliefs about dying and the body. In Japan, Lock (2002b) argues, death is considered to be a gradual process, involving both body and soul or spirit, rather than a single definable event at a given point in time. Buddhist ideas about reincarnation also reflect alternative notions of what it means to have a body. Scheper-Hughes (2000) argues that in the west, death itself has become an ambiguous legally and technically constructed discourse. Rejection of death and a fear of mortality can be seen in discourses, often from the family of a donor, that describe how a donor “lives on” in the recipient(s) of their organs (Lock, 1995).

As part of this, ageing and death itself have been reconceptualised as “technological failure” (Scheper-Hughes, 2006, p510). Discourses of “gifts”, “donations” and “saving lives” are deliberately employed by authorities to encourage greater numbers of people to donate. Yet it has been argued the idea

of scarcity of organs is itself a medical discourse and a creation of technology, the result of surgical and immunological advances that means that as more transplants becomes medically viable, more organs are needed to meet this artificially created demand and the "...unprecedented possibility of extending life indefinitely with the organs of others" (Scheper-Hughes, 2000, p198).

Since kidney transplants between unrelated individuals have become possible due to the development of effective anti-rejection drugs and even more deaths from kidney disease can be postponed, the moral rights of a patient to an organ from another body has become an uncontested discourse. If the organ comes from a deceased person, their bodies are positioned as resources, to be put into the pool for the good for society. Refusing to become an organ donor after death is implied to be irrational, selfish and above all wasteful. Once this reality has been established, it can be argued that the extension of these sentiments to living donors is relatively straightforward, since most of us have after all, a "spare" kidney, which as long as it remains in our body can be described as being "wasted". Altruistic donor Mark Moorhouse draws on this discourse: *"If you carry a donor card, there's no reason why you can't do this now...you don't have to be dead to give someone else the chance of life"* (The Observer, 3.4.11).

A leaflet that can be found in all doctors' waiting rooms and is routinely sent out with NHS mailings asks over the photograph of a smiling mother and her son; "Have you joined the Organ Donor Register? On the back of the leaflet, the picture has changed; the mother looks desperate, and the young man is wearing a hospital gown, seated in a wheelchair, an oxygen tube attached to his deathly pale face; over which run the words: "Would you take an organ if you needed one?" The principle of Mauss' (1954) theory of reciprocity in gift giving is clear and the message is unambiguous; if you would want a donated organ for your fatally ill child, then you ought to be prepared to become a donor after your death. Inside the leaflet are the statistics: "96% of us would take an organ if we need one. Yet only 29% of us have taken action and joined the NHS Organ Donor Register. If you believe in organ donation, prove it" (NHS, 2011). The leaflet goes on to explain that three people die each day waiting for an organ transplant.

Increasing the number of organ donors is an on-going concern for the NHS, as evidenced by the launch of a national organ donation campaign in 2009. The fact that under a third of people are registered organ donors in the UK suggests that in

spite of the biomedical discourses of exchangeable body parts, for a significant number of people there remains something problematical with the idea of giving away organs after death. Medicine's attempt to procure more organs for transplant has to compete with contemporary discourses that relate people's nightmarish fears of the possibility of being "switched off" by doctors while still alive. Media reports of the sudden and unexpected recovery of a patient who had been diagnosed as irretrievably brain-dead by doctors and suitable therefore for organ donation are, if not common, then regular occurrences. Stories abound in film, television and urban myth of people having their organs "stolen" from them and left in a horrifying state somewhere between death and living. The use of the word "procure" in relation to organs itself signals a commodification that is apparently difficult for people to reconcile with the notion of their living bodies. Lock (2002) describes the "technologically manipulated death" that has to take place for organs to be taken from a brain-dead donor (p263). Disturbing questions are posed by organ donation about what it is to be alive, the role of consciousness in living and the idea of "killing the 'person' while preserving the living body" (Lock, 2002a, p263).

A discourse of obligation 'moralises' bodies and body parts and the responsibility to examine the ethics of what is happening is "side-stepped through objectification" (Lock, 2002a, p72). This is discernable in articles written by journalists who need a transplant, or who have had one, and who use their access to the media to campaign for greater numbers of donors to come forward, or for a market in human organs to be made legal in the UK. In these appeals, moral and economic discourses are integrated seamlessly. Writing in *The Times* in 2010, Sally Satel, a grateful recipient of a kidney donated by an acquaintance, argues for a radical overhaul in the way in which organ donation is regulated in the UK. She advocates moving away from an altruism based system to one in which living donors would receive benefits "in kind", in order to meet "the dire need for kidneys". She goes on: "Living kidney donors would be carefully screened for physical and emotional impediments to safe donation and be guaranteed follow-up medical care for any complications" (*The Times*, 11/6/10).

Behind Satel's uncontested intertwining of economic and moral discourses lies this assumption: "If I want something, and I have the resources, I *must* be entitled to have it, and be able to purchase it if necessary. And if the thing that I want is part of another living person's body, then society must be re-organised in order for

it to become acceptable for me to buy that organ.” Understandably, Satel wants to go on living, haemodialysis is miserable, painful and severely limits a patient’s quality of life and health. The assumption behind her argument, that we have an assumed right to *go on living* and therefore it is morally right that other people give parts of their bodies to make that happen, is however powerful and uncontested in the media.

“We live in an unfair world, where health and happiness aren’t evenly distributed, and I’ve had more than my fair share. My act was simply to redress the balance a little.” This is how Maggie Harris, an altruistic donor, accounted for her act in a newspaper interview (The Guardian, 15.5.10). She asked why she should not give her a “*surplus organ*” to “*someone who really needed it*”.

“It was the idea of instantly helping to save a life that appealed”, another altruistic donor, twenty-five year old Luc Delauzun says, continuing, *“I’m not a doctor or a soldier...so the likelihood of rescuing someone is relatively low”* (The Guardian, 25.10.11). “Rescuing”, and “saving a life”; these discourses routinely appear in the slowly increasing trickle of articles about the real-life experience of altruistic donors that is steadily increasing the profile of non-directed “altruistic” donation. The Observer calls altruistic donation “*close to the ultimate selfless act*” and something “*making the difference between life and death*” (3.4.11)”

In other stories, families of deceased organ donors describe gratefully how their tragedy has been turned to good fortune for others, and that through organ donation they are able to think of their dead child as continuing to live on in someone else. Lock (2002) calls this the “fetishism of human organs” and suggests that this discourse is deliberately drawn on in order to promote donation (p72). Scheper-Hughes (2006) draws attention to the ethically questionable imposition of an “obligation” on people to become living organ donors and in another paper (2000) criticises the “medical discourse on scarcity” that she claims drives the market for traffic in human organs. It is an enormously powerful discourse. In response to it, altruistic donors apparently willingly submit themselves to the expertise of doctors, surgeons and anaesthetists.

In November 2011 a new charity was launched in the UK; “*Give a Kidney – One’s Enough*”, in which a retired doctor, himself an altruistic donor, along with other men and women who have donated a kidney in the same way, appealed for more

living donors to come forward and donate to the four thousand patients who are currently waiting for a transplant in the UK. The charity has high profile patrons and the launch generated considerable national media interest. That it is remarkable enough to generate the interest it does however suggests that this “selfless act” is nevertheless still regarded as “extraordinary” (Sky News, 2011). It seems that the public may be simultaneously fascinated yet also on some level disturbed by the concept. The charity’s website is dominated by images of hope and health – a child holding balloons, a young man jumping into the sea at sunset, a smiling, healthy couple in their sixties. These contrast with the page of stark statistics on the thousands of people who are on the waiting list for a kidney and how many die each year waiting. It states that the aim of the charity is to “raise awareness” and “support people who are considering this type of donation”. Altruistic donors give testimony as to the value of what they have accomplished, in compelling terms. They say: “*I knew immediately that this was something I felt I might be able to do*” and; “*Immediately my heart just told me this was something I really wanted to do*” (<http://www.giveakidney.org/personal-stories/giving.html>). Monroe (1996), in a study of notably altruistic individuals, argues that this immediate recognition occurs because altruistic people have a different sense of what is “normal”, describing the spontaneous nature of the decision as “reflexive”, (p210).

2.5.3. The psychoanalytic subject and the body

The methodology of this study draws on a psychosocial research paradigm (Frosh & Saville Young, 2008) which posits that social and the psychic accounts be treated as separate and equally privileged entities (Clarke, 2008). Psychosocial researchers work from within a range of qualitative psychology and sociology perspectives, with various discursive and narrative approaches, informed by an interest in different psychoanalytic theories, including those of Freud, Lacan, Klein and the Object Relations theorists. My understanding is that in spite of this wide set of theoretical resources, there exists a broadly similar epistemological goal of developing a method that is capable of critically exploring the complex interaction of social and intra-psychic factors that occurs when an individual engages with the discursive tools available to them. Frost & Hoggett (2008) characterise the “psychosocial subject” as one “in a world of power relations...with agency, though not necessarily in a position to exercise this reflexively” (p440). The

epistemological and theoretical bases of the methodology of the current study will be discussed at greater length in the next chapter.

Frosh (1999) writes: “The object of psychoanalytic knowledge is subjectivity, the flowing, changing, productive and disjointed experience that each of us has of ourselves and the world, and the pattern of linkages that this subjectivity has with unconscious and with external events” (p9). This focus on subjectivity makes psychoanalysis a rich and compelling resource for Counselling Psychology research. The psychoanalytic subject, self or mind is understood as being a dynamically unconscious one, as well as an embodied one (in which the body includes the brain and conscious experience). While the anthropological and sociological perspectives on the body reviewed in the previous section are interested in the way that bodily manifestations flow in the direction of social to individual, from outside to inside, psychoanalysis is interested in the way in which physical symptoms are generated in the individual mind, from inside to out.

Freud (1923) described the development of the ego in terms of the body. The Freudian psyche interprets and thus is structured by drives and instincts that begin in the body (Lemma, 2010). In Freud and Lacan’s theory, the ego, or “I”, is created to give a reassuring sense of unity to the body and its conflicting drives. But for Lacan, the function of the ego and an “integrated self” is delusional because “...each subject knows that it is not really whole, that this seeming-self is a bare cover for something disturbing” (Frosh, 1999, p144). The ego protects itself from anxiety by repressing or altering feelings that are intolerable through the use of defences. The body may play a central role in these defensive mechanisms. The experience of anxiety or trauma may be translated bodily into a panic attack for instance, with frightening physical symptoms such as an increased heart rate, sweating, and the feeling of not being able to breathe. Depression too, manifests itself physically, with exhaustion or insomnia.

In psychoanalytic thinking about object relations, the way in which we unconsciously relate to our selves and others, the role of phantasy is central. From this perspective, our experience of ourselves, other people and being in the world is mediated through unconscious fantasy. The psychoanalytic subject is constructed through integration of experiences of the real and the fantasised (Mitchell, 2000). Benjamin (1990/1999) argues that object relations theory does not address directly “...the difference between object and other”, and questions

this “unfortunate tendency” to elide the question of what is a ‘real’ other (subject) and what is an internal representation (object) (p184). In her theory of inter-subjectivity, Benjamin (1990) argues that a relational psychoanalysis needs to be able to conceptualise how individuals experience the other as both object *and* subject. The developmental shift from complementarity to mutuality leads to the dismantling of omnipotence and the end of the constant trading back and forth of power in the mother-child relationship, but if mutual recognition is not possible for any reason, then intra-psychic experience dominates and relating is to the internal object at the expense of a genuine inter-subjectivity (Benjamin, 1990).

Psychoanalysis recognises that physical symptoms and illness may, like language, be thought of as a form of unconscious communication that function instead of language, their role is to telegraph the individual’s subjective experience of mind. Illness symptoms can function as communication in cases where language about traumatic feelings is not possible and the feelings cannot be symbolised (Meissner, 2006). Winnicott (1964/1989) describes psycho-somatic illness from a developmental perspective as a “defensive organisation” and emphasises that in such cases, priority should be given to treating the mind over the bodily symptoms:

“Illness in psychosomatic disorder is not the clinical state expressed in terms of somatic pathology or pathological functioning (colitis, asthma, chronic eczema). It is the persistence of a split in the patient’s ego-organization, or of multiple dissociations, that constitutes the true illness” (p103).

Winnicott is suggesting that the ego, or self, in a disintegrated state leads to the physical illness. Meissner (2006) describes how a contemporary Kleinian approach would think of psychosomatic illness as a splitting off or dissociating from the bad part-object in order to separate it from the self, and project it into the affected (ill) body system. The dynamic processes that are unconsciously expressed in physical symptoms represent subjective experiences that cannot be thought about (Meissner, 2006).

In her psychoanalytically informed study of body modifications, Lemma (2010) suggests that for some individuals, making changes to the body (in Lemma’s study, the surface of the body, but I think that this is also relevant to deliberately

changing the internal structure of the body) is a way of defensively maintaining the split between mind and body in which the mind is “self” and the body is “other”. Lemma (2010) suggests that the way in which we relate to our bodies concretely marks the way we feel about ourselves and others and contends that when individuals feel compelled to dramatically change their body, something is being managed in relation to the individual’s feelings towards another (in Lemma’s formulation it is the mother). This may be a way of reclaiming or re-appropriating the body from the other, or a way of attacking the other by disfiguring the self, and Lemma (2010) suggests that if the individual is not able to enact this phantasy, they are unable to hold onto a feeling of integration and the sense of self is unbearably fragmented.

D.2.6 Aims of current research

My aims for this qualitative study are twofold. Firstly, I want to explore how prospective altruistic kidney donors discursively construct and position themselves when asked about their decision to donate a kidney. Secondly, in the context of this socially constructed analytic framework, I want to engage with the intra-psychic and inter-subjective aspects of participants’ decisions to become altruistic kidney donors and to reflexively explore whether it is possible to provide a theoretically meaningful, non-pathologising interpretation of participants’ subjectivity.

This methodological approach takes a social constructionist approach to language and incorporates the following theoretical ideas: A Foucauldian-inspired treatment of the discourses that relate to altruistic kidney donation has been presented above (Hook, 2007). In the analytic strategy I have also drawn on Wetherell & Potter’s (1992), and Wetherell’s (1998) psycho-discursive approach, focusing on interpretive repertoires and the subject positions made available. Finally, I have included a psycho-dynamically informed analysis of three participants’ emotional investment in the discourses and subject positions they take up during the research interview (Frosh & Saville Young, 2008; Frosh & Emerson, 2005; Parker, 2005). These analytic strategies have not been applied in a linear fashion, as this proved to be unworkable. Instead I have found that I have needed to move backwards and forwards between the two, in a reflection of the epistemological tension that exists between the social and intra-psychic perspectives. In applying

the different levels of analysis, I have found it useful to consider Britton's (1988) 'third position' approach to theory as a way of moving between analytic positions.

Broadly, my intention in choosing this integrated approach to methodology has been to try to reflexively address the ethical problem of being directly implicated in the power relationships that reside in the "institutionalised hierarchies and discourses of pathology" (Frosh & Emerson, 2005, p310). This is important because although this study is rooted in the non-pathologising, pluralistic practice of Counselling Psychology (Rizq, 2010), and I hope to be able to suggest an alternative account of altruistic donor motivation to that which currently exists in the literature, it must be explicitly acknowledged that it is also unavoidably confined by a particular discursive backdrop and that any alternative account has unavoidable epistemological limits on it.

Another factor driving the psychosocial approach of this study is the epistemic question of whether it is possible to make genuinely bottom-up, psychologically meaningful interpretations from talk. I am drawn to Frost & Hoggett's (2008) description of the psychosocial paradigm as one in which the subject is conceptualised as "ambivalent and emotionally driven" and defined by, but not existing solely, in language (p440). One level of interpretation in this study therefore incorporates the use of relational psychoanalytic theory, firmly grounded in interview text and reflexive practice. I am mindful that in using psychoanalytic ideas in research there is a risk of a deterministic, top-down interpretation (Parker, 2005; Frosh & Baraitser, 2008), the imposition of a pathologising alternative discourse on participants' own discourses, and for the boundaries between research and clinical practice to become blurred (Kvale, 2003). This awareness has provided the starting point for reflexive work in this study.

D.2.7. Research questions

The main research questions:

- i) How do the participants use discourses or discursive repertoires to construct altruistic kidney donation?
- ii) What subject positions, practices and possibilities for subjective experience do these donor discourses allow?
- iii) Why these discourses? Is it possible to explain donors' emotional investments in their discursive positions using psychoanalytic theory?

D.3. METHODOLOGY CHAPTER - PSYCHOSOCIAL RESEARCH

D.3.1 PART ONE – METHODOLOGY

3.1.1. Reminder of research questions

In this section, I develop an argument for the epistemological stance taken in the current study. The research questions to be addressed in this study are:

- i) How do the participants use discourses or discursive repertoires to construct altruistic kidney donation?
- ii) What subject positions, practices and possibilities for subjective experience do these donor discourses allow?
- iii) Why these discourses? Is it possible to explain donors' emotional investments in their discursive positions using psychoanalytic theory?

3.1.2. The turn to language – social constructionism

This study takes a social constructionist approach. According to Burr (2003), a social constructionist research paradigm rejects positivist notions of empirical investigation and the existence of an essentialist, fixed external reality that can be definitively described or proved. Instead, social constructionism takes a critical approach to knowledge and assumes that individuals construct historically and culturally specific accounts of the world, representing it in thought and in communication with others, using language or other symbols (Burr, 2003). The role of language is therefore central. Social constructionist psychology posits that language precedes thought, since it is culturally specific concepts and categories that provide the building blocks and frameworks of meaning for the way individuals think and speak. The widely observable fact that different traditions and professional disciplines have different ways of describing the same object illustrates this argument, according to social constructionist theorist Kenneth Gergen (2009). This means that research from within a social constructionist perspective is not concerned with providing a true versus false account but is interested in how facts are constructed in society as facts and the consequences these particular constructions have for people (Wetherell & Potter, 1992).

A focus on language leads to arguments about what, if anything, can be definitively known about the internal experience of being human, with highly significant implications for the theory and practice of psychology in terms of whether it is ever possible to understand in any meaningful way the subjective experience of another individual. In contemporary psychoanalytic theory, subjectivity is assumed to be the result of the integration of fantasy and reality, and as such can also be thought of as constructivist in its understanding of reality (Mitchell & Aron, 1999). In strict relativist terms, Gergen (2009) contends that the way we think and talk about ourselves and others is determined not by any singular material reality, but solely by practice traditions, and it is therefore social relationships that determine how we come to know the world. This suggests that we make meaning of our internal and external worlds through our relationships, and the inter-subjective epistemology of social constructionism can circumvent the hermeneutic problem of validity in interpreting language (Gergen, 2009).

“One’s performances are thus possessions not of the mind but relationship; they are inhabited not only by a history of relationships but as well by the relationships by which they are directed. By making these two theoretical moves, first treating psychological discourse as performance and then embedding performances within relationships, we are now positioned to see the entire vocabulary of the mind as constituted by and within relationship. There is no fully private self, as in the traditional accounts. Rather, there is embodied action, and such action has meaning within and because of relationship” (Gergen, 2009, p100).

A relativist approach of the social constructionist perspective has been criticised by Cromby & Nightingale (1999), who argue that in psychology, the “turn to language” has led to a failure to account for power, materiality and embodiment, arguing that it is neither possible nor desirable to reduce all aspects of life to discourse. Parker (1992) takes a similar critical realist approach to discourse, critiquing “the mistaken idea that discourses create all we know and could know...” (p25). Burr (2003) contends that a social constructionist psychology must be able to address individual differences in selfhood and embodiment if it is to be considered actually psychological and not leave us with “an empty person” (p119). In arguing for critical-realist ontology in social constructionist psychology, Nightingale & Cromby (1999) cite the problem of experiences for which we have

no words, the times when “our lives are more than we can say” (p222). The research questions in the current study aim to take account of these criticisms of a relativist social constructionist epistemology by attending to subjectivity.

3.1.3 Foucault and discourse - relevance and limitations

In a review of recent research that is grounded in the thinking of Michel Foucault, Miller (2008) suggests that Foucault is interested in how discourses, or ways of knowing, bring people and various realities into being and the social consequences of those ways of being. Foucauldian discourse analysis is therefore interested in how discourses are used in the production of subjectivity and selfhood and the power relations that are the result of language in relationships (Burr, 2003). It incorporates the idea that discourses influence how ideas are applied and regulated in practice by experts.

The current study draws on Foucault’s (1980) concept of discourse as a system for representing knowledge at particular historical, social and cultural junctures. Foucault (1978) contends that different institutions produce a multiplicity of discourses and the knowledge represented by discourses is then recruited into power relations in institutional settings such as medicine, law and psychology. Wetherell & Potter (1992) draw on this notion of discourse or discursive practice as actively “constitutive” of social and psychological processes and propose that the aim of discursive psychology is to look for the processes by which claims become communicated as fact and thereby empowered as “truth” (p62).

Foucault (1978) traces the point at which the human body and living, rather than simply death, became subject to power relations, to the seventeenth century in Europe; “...it was the taking charge of life, more than the threat of death, that gave power its access even to the body” (p143). The result, Foucault (1978) suggests, is that: “A normalising society is the historical outcome of a technology of power centred on life” (p144). The body is the site of this disciplinary power; the activities of individuals are bounded and defined by institutions such as medicine, psychiatry and the law, and those who violate the boundaries are punished (Coupland & Gwyn, 2003). For Foucault though, power is not necessarily repressive, it can also be productive and it is for this reason that people at times accept power and willingly seem to participate in taking up a clinical gaze.

The “discursive construction” under scrutiny – the practice of altruistic kidney donation in the UK – is situated in a particular medical context in which assessment of the donor by a psychologist is a largely unquestioned aspect of the process. The explicit intention of assessment is to protect the donor from psychological harm as a result of their action, yet there are many practices that individuals engage in that offer the prospect for psychological harm in which assessment is not required by society or the law. In line with Arribas-Ayllon & Walkerdine’s (2008) description of the importance of a genealogical approach to Foucauldian research, I want to draw attention to the role that the historical medicalization of the body and the mind plays in this assumption, the implications for power relations that exist within this medicalization, where one individual is invested with power through “knowledge”.

Psychology as a discipline has contributed to this construction of distinctions between “sanity” and “madness” which is inherent in the practice of psychological assessment. According to current psychological and practice, this particular intention on the part of an individual is taken to suggest the possibility of “madness”. Although it is beyond the scope of the current study, one goal of a full Foucauldian inquiry would be to interrogate this assumption, charting the history of the medicalization of the body, and the historical antecedents of assessment in psychology and medicine. In this way, it could be shown how historically specific social constructions have led to the assumption that the desire to give away an internal organ is a possible indication that the individual is not thinking “normally”.

Before 2006, altruistic non-directed kidney donation was not legal in the UK but with a change in the law, official discourses of individual, medical and legal capacity were amended in order to permit what had hitherto been a practice defined as an unacceptable medical practice. I argue that this is consistent with Foucault’s description of a “regime of truth” (1980, p131).

“Each society...has its general politics of truth: that is the types of discourse which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true” (Foucault, 1980, p131).

Following Hall's (2001) description of the operation of a 'regime of truth', if it is believed by health professionals, regulatory bodies, the public, that wanting to donate a kidney to a stranger is not a "sane" or rational thing to do, then the would-be donor needs to be protected from harm. According to Foucault (1980), related practices will mean that this becomes true in its effects and the practice is made illegal, confirming that anyone wanting to pursue this practice is misguided, or may even be "mad". In this way, Foucault allows us to look at the ways in which psychology becomes a "subjectifying form of power-knowledge" (Hook, 2007, p2). Hook (2001) argues that Foucauldian discourse analysis in psychology research must be genealogical in approach and refer to materiality, without which discourse analysis is merely "a decontextualized set of hermeneutic interpretations" (p542).

This relationship between psychological "knowledge" and power has obvious implications for the practice of living organ donation, recruiting professionals who are tasked with carrying out psychological and medical assessments and risks subjectifying donors who come forward wanting to donate a kidney to a stranger. In terms of practice, it seems that many health professionals simply do not know what or how to think about altruistic donation. It is also interesting that in the discourses surrounding altruistic kidney donation, the recipient is generally silent, positioned from the start as a victim. This tension that is inherent in the practice of altruistic donation is interesting in the context of Hook's (2007) description of Foucault's approach, in which we are required to "reassess notions of a natural universal psychological subjectivity" (p4).

3.1.4. Debates about agency and subjectivity

The concept of psychological subjectivity is a problem for Foucauldian thought. Foucault is "anti-hermeneutic", meaning that he makes no attempt to look for actual meaning, and what we understand as "truth" is a representation of "powerful knowledge" with which subjects are created (Wetherell & Potter, 1992, p81). Foucault (1980) advises getting "rid of the subject itself", in contrast with a phenomenological epistemology and its focus on the subject (p117). Foucault (1982) seems to be saying that individuals' constructions of subjectivity are bound by readings of discourses that are determined by others, producing subjectification rather than subjectivity. But Burr (2003) suggests that by using self-reflection and common sense we can argue with Foucault's stance and say that individuals can and do actively appropriate discourses to their own ends

(Burr, 2003). Hall (2001) also questions Foucault's account of the fixed nature of the subject positions that are available to individuals through the use of discourse, and argues that accounting for individual agency is problematic in Foucauldian discourse analysis. Hollway (1989) suggests that Foucauldian analysis is not able to account for individual differences in adopting discourses, while Wetherell (2005) calls this problem the "agency/structure debate" in social psychological research (p169). Wetherell's (2005) solution to the dilemma of agency is to suggest that it is most usefully thought of as a discursive resource, to be sometimes recruited by individuals, in the same way they sometimes construct their behaviour in terms of external determinants.

I argue that a similar tension is also of theoretical interest to counselling psychology, which can be argued to occupy a similarly uneasy position of striving to privilege agency and subjectivity, whilst operating within an existing knowledge/power infrastructure of the current psychological and psychiatric 'regime of truth'. Miller (2008) suggests that in his later work, Foucault does in fact offer what seems to be greater scope for agency with a focus on *ethical* ways of being and morality as a way of self-governance, or relationship to the self. This later Foucauldian emphasis on individual ethics and morality – "the technology of the self" (Miller, 2008, p19), grants greater freedom to individuals to reflect on how they are subjectively positioned in relation to discourses and power, but it is nevertheless still "a freedom within limits" (p265). Willig (2005) agrees it is possible to take a Foucauldian stance to the way in which individuals are "constituted by historically and culturally specific discourses and practices, and at the same time acknowledge that this subject experiences him/herself as thinking, as feeling, as embodied" (p32). Willig (2005) argues that integrating Foucault's genealogical method with an interest in the subjective experience of individuals in this way is valuable because it enables us as practitioners to explore "alternative subjectivities" with the people we work with (p33). At this point I am drawn to Frost & Hoggett's (2008) psychosocial concept of the "social subject with agency, though not necessarily in a position to exercise this reflexively" (p440).

Parker (1999) argues that a critical realist psychology needs to emphasise agency, phenomenology and self-awareness, and suggests that Foucault's constructionist "regime of truth" fails to accomplish this. Yet a purely humanist approach to research is also unsatisfactory, according to Parker (1999), as it relies too heavily on phenomenology and neglects discussion about the ways in

which individuals construct subjectivity. Parker suggests that in order to reconcile these epistemological weak spots, psychology researchers need to reflect critically on the use of theory and analytic strategies and describes the need for “a critical reflexive humanist approach in constructionist psychology” (1999, p24).

3.1.5. *Positioning theory and interpretive repertoires*

Willig (2008) describes how various theoretical and non-theoretical concepts have been applied to discourse in order to provide a more satisfactory account of subjectivity in discourse analytic research. Davies & Harré’s (1990) theory of positioning is one such approach to discourse analysis that can also be used as a way of engaging with the active role the individual plays in choosing discourses: “A subject position incorporates both a conceptual repertoire and a location for persons within the structure of rights for those that use that repertoire” (p262).

Davies & Harré (1990) contend that individuals are constructed through using a multiplicity of sometimes contradictory discursive practices but these are not completely constraining, allowing the individual to choose whether to engage or not with them depending on the subject positions they can provide: “...the stories through which we make sense of our own and others’ lives” (p263). Burr (2003) suggests that positioning theory allows us to think about the subjective experience of discourses and therefore ourselves, describing how when individuals use discourses in social situations, others are also positioned, intentionally or otherwise. We may resist the positions we are placed in and negotiation may be required until both parties are satisfied with the positions available to them (Burr, 2003).

Positioning theory can therefore be argued to offer a partial solution to the ‘agency problem’ in Foucault’s thinking and will be used in the current study to explore the ways that individuals *actively* negotiate and construct their subjective experience (Burr, 2003). This notion of positioning in discourse analysis is supported by Parker (1999), who suggests that when accounting for individuals’ use of discourses, it is necessary to consider how available discourses lead to the creation of “spaces” for certain things to be said and positions taken, and conversely, also prevent other things being said and alternative positions being taken.

Wetherell (1998) however, questions whether discourse is in fact the 'active agent' in positioning, suggesting that it is participants' accountability and the conversational activity that emerges from it that drives positioning; "...what a subject position comes to be is only partly the consequence of which discourse it can be assigned to" (p401). In place of the Foucauldian notion of discourse, Wetherell (1998) uses the more situated concept of 'interpretive repertoires' – "a culturally familiar and habitual line of argument comprised from recognisable themes" (p401), arguing for the analytic focus in discourse analysis to be on actual social interaction.

Wetherell (1998) and Potter & Wetherell (1987) argue for a synthesis of discursive and Foucauldian-inspired influences to create a more useful analytic approach to discourse. Wetherell (1998) suggests a stance in which Foucault's post-structuralist theory of discourse and a focus on talk-in-interaction derived from conversation analysis can be read in terms of the other. This leads to the understanding that in any interaction between people, many subject positions are available to be taken and that discursive practices constitute subjectivity, including psychological states and identities, in a genealogical context (Wetherell, 1998). Thus in addition to Foucauldian theory, Wetherell's (2005) "psycho-discursive" practices provide a useful analytic approach for the current study (p80).

3.1.6. *The turn to the relational – the psychosocial research paradigm*

Psychosocial methodology offers a third approach to reconciling the conceptual gap between social constructionist epistemology and critical-realist ontology, and is capable of theorising subjectivity. Frosh (2003) describes how psychosocial research aims to account for what happens to a person from both social and psychological perspectives and of how they make meaning from it:

"Both bound and free, more than what forms them yet only existing as a consequence of the constructing processes of sociality – this is the painful state from which human subjects have to use agency and imagination to make something of themselves" (p1553).

Frosh, Phoenix & Pattman (2003) describe how psychosocial methodology integrates psychoanalytic theory on inter-subjectivity and the co-constructed nature of relationships with a Foucauldian approach to constraining discourses,

and the way that identity positions and power relationships are enacted through them. In this way, Frosh, et al. (2003) suggest that it is possible to provide an account of the discourses with which participants position themselves (the social) and to tentatively suggest reasons for that individual having chosen those discourses (the psychic) that is grounded and observable in the text and the research relationship. The psychoanalytic subject is formed through language. In psychoanalysis too, there is a focus on the subjective experience of the individual, and the role of language in this, rather than an attempt to discern what is 'true', meaning that social constructionism and psychoanalysis, from this perspective, whilst not exactly complementary are at least capable of co-existing.

This integrated methodology can therefore to be argued to address the failure of a purely social constructionist discourse analytic approach to give an account of people's subjective experience and events (Parker, 1999, Burr, 2003; Frosh et al., 2003) and offers the possibility of an ontological stance capable of explaining phenomena relating to the self and agency in psychology. Rather than doing away with the subject, as Foucault (1982) would have us, psychosocial research is interested in "conceptualising... a type of subject that is both social and psychological, which is constituted in and through its social formations, yet is still granted agency and internality" (Frosh & Baraitser, 2008, p349).

In an example of this type of study, Hollway's (2008) research into women's identity as first-time mothers uses a psychoanalytic approach to objectivity and subjectivity, combining this with positioning theory, to argue that the relativism-realism debate outlined above can be avoided. Hollway & Jefferson (2005) describe how psychosocial research takes account of the specific situation of the subject, arguing that Foucauldian power relations are mediated by the individual's unique biographies, in line with positioning theory (Davies & Harré, 1990). Wetherell's (2005) exposition of a critical discursive methodology, while not called psychosocial, seems to have strikingly similar methodological aims to the psychosocial approach of Frosh & Saville Young (2008).

Wetherell (1998) argues that good discourse analytic research aims to attend to "the formation and negotiation of psychological states, identities and interactional and inter-subjective events" (p405). Wetherell (2005) also argues that individuals are reflexively embedded in social practices that are relational and inter-subjectively constructed, at the same time as being capable of actively "mobilizing

and reworking” these practices (p170). In line with this, psychosocial research engages with the idea that subjectivity is constructed socially, including importantly, in the research setting (Frosh, 2003). Frosh et al. (2003) propose that when individuals describe their lived experience, both social discourses and the individual’s particular struggle for agency can be observed as they locate themselves in relation to discourses, and the psychoanalytic concept of the unconscious plays a part in this struggle, asking “...what structures discourse at the level of the personal?” (p42).

3.1.7. *The role of psychoanalytic theory in the psychosocial paradigm*

Clarke (2008) describes psychosocial research as having its roots in Habermas’ (1971) description of psychoanalysis as a depth hermeneutic tool, addressing both conscious and unconscious forces, based in self-reflection. There is a tension in trying to integrate the hermeneutic approach of psychoanalysis used in this way, with the anti-hermeneutic approach of Foucault. One way to reconcile a Foucauldian approach to discourse with psychoanalytic interpretation is to use Lacan’s theory. Frosh (2006) describes how Lacan’s mirror stage is a description of the way an individual’s developing self inevitably incorporates “the meanings of the other” (p185) and that this happens because for Lacan, in the *real* self, cohesion is not actually attainable. Notions of “identity” and integration are therefore, according to Lacan, a fantasy, a way to artificially cohere the fragmented internal self. The mirror stage is fatally interrupted by the symbolism of language as it “interferes” with the individual’s understanding of their own emotional experience (Frosh, 2006, p185). Language, from this perspective, disrupts subjectivity.

Billig (1997) argues that there is a conceptual mismatch between the discursive assumption of the external (social) availability of language with the internal, unconscious and therefore unavailable processes that are of interest to psychoanalysis. However, Frosh (2006) proposes that psychoanalysis is useful for understanding how people act and how they make meaning from the social world through its attention to fantasy and because it aims to “make sense of the subjective determinants or impact of a set of phenomena: the ‘meaning’ of an event for people, its resonance and its threat” (p170). Psychoanalysis therefore offers answers to “questions of motive, interest, investment and desire...” (Frosh & Emerson, 2005, p322).

In an early psychosocial study, Hollway & Jefferson (2000) developed a methodology that focused on the idea of the “defended” research participant: “The idea of the defended subject shows how subjects invest in discourses when these offer positions which provide protections against anxiety and therefore supports to identity” (p23). However, in a move that is now considered ethically problematical, Hollway & Jefferson (2000) used a Kleinian concept of researcher counter-transference to provide them with information about participants’ unconscious subjectivity. This approach has been criticised by Parker (2005) because of the way in which it imposes the authors’ own meanings, describing psychoanalysis as “a master narrative that demands absolute obedience once it has been allowed in” (p108).

Walkerdine, Lucey & Melody (2001) also draw on psychoanalysis in research and argue that the discourses with which people construct their identity and experiences “work in and through desires, anxieties, defences” (p83). They ask how an individual’s subjectivity constructed through discourses is used as a defensive mechanism, and try to think about what is being defended against. Walkerdine et al. (2001) describe an interpretive process that is similar to way a psychodynamic therapist aims to use counter-transference thoughts and feelings in order to understand the unconscious communication of their client. The use of counter-transference in research is ethically problematic for Frosh & Baraitser (2008), who argue that there are important differences between the research situation and the therapeutic relationship, citing the fact that in research, the participant has not come to the researcher asking for help with intra-psychic conflict. Instead, it is the researcher who has sought out the participant and intersubjectivity in this context should not therefore be considered to be the same as the transference-countertransference in the therapeutic relationship.

Frosh & Emerson (2005) caution that the notion of the defended subject is a top-down use of theory that does not emerge from the text and as such should be avoided if possible. Frosh & Baraitser (2008) warn that psychoanalysis ought not to be used as a way of better understanding the subject in qualitative research. Wetherell (2005) too, is critical and suggests that it is important to think about the discursive context of the interview and the “attributional demands” this places on participants, questioning the placing of people in storylines not of their choosing for both ethical and epistemological reasons (p171). In arguing for the importance of attending to notions both of identity and subjectivity in discursive research,

Wetherell (2008) warns that Hollway & Jefferson (2005) over-emphasise subjectivity, and thereby neglect the social: "We are left with a person out of context, pulling meaning from mind, from out of the psychological depths" (p79).

In response to problems outlined here, Frosh & Saville Young (2008) describe a psychosocial methodology that theorises the internal dynamics of subjectivity as permeated by the social. This is the particular approach to psychosocial methodology that I have chosen to use in the current study and therefore emphasises avoiding the deterministic imposition of theoretical concepts on participants' experience (Frosh & Saville Young (2008).

I have endeavoured to hold in mind Parker's (1992) warning against simply using an alternative discourse to interpret the experience of research participants. Frosh & Baraitser (2008) question whether applying psychoanalytic theory to the interpretation of participants' life stories, with its deterministic emphasis on development, is appropriate, suggesting that it leads to "predictable motivational accounts and interpretive strategies" (p353). This is consistent with what Burr (2003) says about social constructionist research: "The subject's own account of their experiences can no longer be given an alternative interpretation by the researcher who then offers their reading as the truth" (p155).

Frosh & Emerson (2005) highlight the dangers of over-interpretation and offer a reflexive critique of the psychosocial paradigm by presenting parallel analyses of an interview, one psychoanalytically informed and one discursive. They stress that the danger of applying psychoanalytic assumptions to the text is that alternative constructions may be prevented and that this is incompatible with a methodology that aims to give equal attention to the agency of the subject. In their paper, a psychoanalytic framework is employed extremely tentatively, and instead of suggesting structural explanations for the content of the participant's story, instead uses carefully-worded interpretations of the possible here-and-now investment that the participant makes in choosing discursive positions for "negotiating psychological conflicts, with their associated anxieties and desires" (Frosh & Emerson, 2005, p313). In the current study, the use of more than one level of analysis is intended to provide a way to limit the imposition of a psychoanalytic understanding on participants.

3.1.8. *The use of psychoanalysis in this research*

The current study draws on relational psychoanalytic theory, which Layton (2008a) describes as being interested in making explicit the “nature of mutual enactments and how we get ourselves out of them”. I am interested in the idea that altruistic kidney donation may be theorised in this way. A relational approach to psychoanalysis places subjectivity at the heart of its ontology, arguing that an individual’s subjective experience is constructed from external, social factors as well as unconscious (internal) fantasies, meaning that we are “always internally and externally imbricated with others” (Layton, 2008b, p66). It can therefore be described as being part of an object relations tradition, and draws on Kleinian ideas of object relating in fantasy and projection as a form of communication. Wetherell (2008) describes relational psychoanalysis as a theoretical approach to describing how individuals construct meaning.

A relational ontology links the psychoanalytic theory I will be using with critical realist social constructionist epistemology. Stopford (2004) makes an argument for using relational psychoanalysis in psychosocial research because of the equal emphasis this perspective gives to inter-subjective and intra-psychic phenomena. Hollway (2008) suggests that the relational turn in psychoanalysis and the notion of identification can provide an ethical means of interpreting socially situated subjectivity in the research participant. She outlines a relational ontology that draws on the idea of everyday unconscious communication in which individuals are capable of discerning or identifying with the emotions, experiences and meanings of another human being (Hollway, 2008). The relational psychoanalytic paradigm is a two-person psychology that departs from the traditional drive theory of Freud by emphasising how inter-personal experiences and constructions underlie development and unconscious phenomena (Layton, 2008a). Interpretation in relationships, including both therapeutic and research relationships is therefore constructed *between* people and is not available for the therapist or researcher to interpret in the traditional sense of being able to “diagnose” the psychological structures of an individual. This form of psychoanalytic theory is essentially hermeneutic in its epistemology (Frosh, 2006) and I argue here and elsewhere in this portfolio that it is consistent with the discipline of Counselling Psychology.

3.1.9. *The decision to use multiple levels of analysis*

At the start of this piece of research, I was interested by Foucault's idea of assessment as a disciplinary method of control (Hook, 2007; Miller, 2008), and wanted to use it to explore the power relations that reside in conflicting constructions of donors' motivations. Power relations are in effect when an individual applies to become an altruistic kidney donor and 'experts' such as physicians and psychologists are required by law to make an assessment of their mental health and motivation for altruism. Psychological assessment is used to determine whether the donor will be allowed to go ahead with the procedure. Psychologists, along with other health professionals can therefore be thought of as operating as "moral gatekeepers", deciding whether an individual is "healthy" enough to take the risk involved in an operation (Beauchamp & Childress, 2001, p49).

In the case of altruistic donation however, the power relations that are played out in the categorisation of "normal" versus "non-normal" feelings and behaviour defy a straightforward definition. The relationship between the donor and the psychologists and medical doctors can be argued to constitute part of the "psy-complex" that Rose (1985) describes. However any process in which psychologists and doctors are required to decide whether to enable an individual, who wants to put themselves in a potentially harmful position in the name of helping another is ethically complex and ought not to be reduced to a discussion of power in one direction. The donor also retains considerable power in this relationship, and it is worth asking if what the medical professionals are being asked to do might be conceptualised, possibly, as an abuse of their own professional ethic. By positioning altruistic donors as victims of power relations, there is a risk of advocating a practice in which anybody who wants to give away bits of themselves must be helped to do so. As such, I am interested in the points at which an individual's desire to donate a kidney to a stranger meet resistance both socially and from individuals, and what this might imply for the way we understand and apply the discourses surrounding altruist donation; the subject positions and subjectivity they allow. A psychosocial approach to analysis focuses on both the social *and* the personal (intra-psychic and inter-subjective) levels.

In addition to this psychosocial framework, I have also been guided by Wetherell's (1998) "eclectic" approach to psycho-discursive discourse analysis, in which she

advocates focusing on the ways in which psychological states, inter-subjective events and identities are formed and negotiated through situated discourse in a genealogical context. Within this epistemological framework, Wetherell & Potter (1992) draw attention to the importance of questioning the status of discourses that are used by the researcher. To that end, they recommend that my discourses must be given equal status as an object of inquiry as those of the participants. Everything that I say is “equally a discursive construction” (p66). Consistent with this, Frosh (2003) describes how psychosocial research engages with the idea that subjectivity is constructed socially, including in the research setting. This means that psychoanalytic concepts ought to be used reflexively rather than as an interpretive lens (Frosh & Baraitser, 2008). They suggest that the most defensible and useful role for psychoanalytic theory in research is as an approach to reflexivity that scrutinises and emphasises inter-subjectivity in the research relationship. Parker (2005) concurs, suggesting that we “treat psychoanalysis dialectically, as part of the problem and part of the solution; it is our way in and out of the contradictory shape of contemporary subjectivity and social relationships” (p108).

3.1.10. *Reflection on methodological changes over the course of the study*

According to Frosh & Baraitser (2008), reflexivity in qualitative psychosocial research means thinking about how the participant uses the research situation and the presence of the researcher to actively construct their conscious experience, describing how “...what the subject “knows” shifts as a result of the interview, as it is co-constructed in and through the interchange with the researcher” (p358). This suggests that in a research relationship, the participant constructs discourses specifically for the researcher at that moment, and as such must be interpreted through a constant reflexive cycle. It means that I must engage with, and reflect on the ways in which I am implicated in the participant’s construction of subjectivity.

Frosh & Baraitser (2008) suggest that reflexivity in psychosocial research requires scrutiny of the text produced not just by the participant but also through the research relationship. Reflexive practice has to be incorporated into the procedure at every stage of the research; including the interview set-up, communication with participants, differences between researcher and participant and what effect these might have, and the ways the researcher may influence the participants meaning-

making through her responses in the interview for example. In practice, this means giving my questions equal emphasis in the analysis and places the current research within a social constructionist reflexive tradition. Burr (2003) argues that a social constructionist paradigm requires the researcher to reflect on how theory may be used to re-order participants' subjectivity and the status of their accounts.

Frosh & Saville Young (2008) point to the risk of circularity in the application of psychoanalytic ideas to discourse analysis because of the way that psychoanalysis and biomedical discourses have become embedded in the dominant cultural discourses available to individuals when they construct themselves. Parker (2005) also draws attention to the way in which psychoanalytic discourse positions individuals and how the reader is thereby invited to read the material in a certain way and is thereby inevitably also positioned by it. This requires the researcher to continuously think about how people are positioned by the theoretical structures that both participant and researcher draw on (Frosh & Saville Young, 2008). I have questioned whether it is appropriate for me to use a psychoanalytic framework to inform my research. Parker (2005) advocates treating it more like a resource than a theoretical framework.

Reflexivity in psychosocial research requires the researcher to examine and utilise the self in much the same way that the counselling psychologist is urged to make use of, and be able to critically appraise the self in the therapeutic relationship. This means being aware of how interventions may encourage some responses and inhibit others. I have had to address the ways in which I may have suppressed discourses through my use of language and para-linguistic practices (Yardley, 2008). In line with this, Clarke (2008) advocates "a critical examination of the relationship between researcher and researched" (p119). This view is echoed by Frosh & Saville Young (2008) who argue that reflexive practice means explicitly acknowledging how the researcher might have elicited a particular response or narrative from the participant.

From a psychoanalytic perspective, this requires awareness of the fact that there may be unconscious material that is unavailable to reflexive practice and to include this awareness of not knowing in the process. As a way of addressing this problem, Frosh & Saville Young (2008) describe how a process similar to clinical supervision may help, with the aim of making clear the researcher's investment in

the research involving “the possibility of interpretation of the researcher’s activity and checking out the impact of this interpretation on her or his understanding and future conduct” (p113). In the current study this has been addressed by a process of detailed exploration of my interpretations of the interview text with my academic supervisor.

Hollway (2008) describes the reflexivity required in this methodology saying that “...the objective use of subjectivity is a challenge involving knowing the difference between myself and the person or situation I am trying to understand”, adding that this is unlikely to be ever completely achieved (p151). In line with the arguments outlined above, I feel that it is important to acknowledge that from the inception of this research, beginning with the decision to make them the subject of the study, I have inevitably positioned altruistic donors as somehow “other”, or different to me and to the majority of individuals who do not choose to altruistically donate a kidney. Reflexive practice has also led me to identify a feeling of anxiety that the idea of altruistic donation elicits in me which will be explored in the analysis.

One possible explanation for this response to altruistic donors is the positioning of the donor as “good” and therefore, everyone else, including me, as “not as good”. The question must therefore be asked; is my interest in participants’ possible motives an enactment of my own anxiety and defended-against feelings? I have considered whether this anxiety may also be reflected at an institutional level in the medico-legal assessment process. This reminds me of the risk in the current study of pathologising the donor’s decision, in much the same way as the medical and psychological literature seems to. As Hollway (2008) suggests, I am unlikely to be able to satisfactorily answer these questions, but keeping them in mind is nevertheless important when I am carrying out interviews and analysing text.

Finally, the inter-subjectivity described by Frosh & Saville Young (2008) has been an important influence for me. A focus on inter-subjectivity requires me to reflect on how the participant and I co-construct reality throughout the entire research relationship and to incorporate this reflexivity in the textual analysis. In this respect, I argue that psychosocial methodology is consistent with pluralism and focus on inter-subjectivity in counselling psychology practice, and it is from within the perspective, discourses and social constructions associated with being a trainee practitioner-researcher that I have chosen this methodology.

D.3.2. PART TWO - METHODS

3.2.1. Design

This research utilises a multiple case-study design (Rosenwald, 1988). Biographical-narrative semi-structured interviews with a small, purposive sample of six would-be altruistic donors provided the text for analysis. This design was intended to elicit discourses to be analysed from multiple perspectives that have been described above. To recap, these are a Foucauldian approach to discourse, a more situated psycho-discursive approach, and a psychoanalytic understanding of the possible psychological meaning of these discourses for participants. The aim was to consider both the implications of discourse for subjectivity and practice, and to suggest a tentative, theoretically driven explanation for psychological investment in particular discourses (Frosh & Saville Young, 2008).

3.2.2. Ethics

The research proposal for the study is included as an appendix (Appendix D1). The original proposal included interviews with health professionals but after completing the altruistic donor's interviews I felt that additional interviews would generate an unwieldy amount of text for a study of this length. Ethical approval was granted by a City University Ethics Committee (Appendix D2). After receiving ethical approval from the university, ethical approval was sought from the NHS using the Integrated Research Application System (IRAS). An online submission was made at <https://www.myresearchproject.org.uk>. After appearing before the committee, I was asked to supply two additional participant documents and a clarification of the recruitment process. On provision of these amendments, ethical approval was given (See appendices D3, D4 & D5). The research was also approved by the hospital's Research & Development office and the trust agreed that the hospital would act as a Participant Identification Centre (PIC) (Appendix D6).

The participant recruitment procedure developed largely out of ethical considerations in the planning stages of the research. As reviewed in the previous chapter, prevailing discourses available in the academic literature tend to focus on the risks of altruistic donation with respect to psychopathology and bio-medical ethics. This is to safeguard the individual and to protect the hospital trust from

legal action. Inevitably, these “official” discourses impacted on the way I approached the recruitment of participants and this illustrates the extent to which the study is inevitably positioned within contemporary discourses of altruistic donation.

My main concern was the possibility of a situation of risk arising in which I would need to break participant confidentiality. I was thinking here of the possible disclosure of information that I considered might have a bearing on a participants’ psychological wellbeing after donation, in other words, the same risk issues that are considered in counselling psychology practice. Initially, after consultation with my academic and clinical supervisors, I decided that I would share any concerns that arose with the hospital’s head of renal psychology and that this would have to be made explicit to the participant before consent was asked for. Subsequently however, I was given the opportunity to sit in and observe the psychologist carry out a clinical assessment interview with a prospective altruistic donor. Two things became clear from this experience. Firstly, the assessment was so thorough that on reflection it seemed to me extremely unlikely that anything new pertaining to risk or future harm to the participant would arise in a research interview. Secondly, the donor whose assessment I attended was highly sensitive to issues of privacy and confidentiality, and I believe that had this donor been one of my participants and I had explained that material might be shared with an assessing psychologist, she and possibly others, would likely refuse to take part in the research or the interview would be distorted, resulting in impoverished data.

As a result, I changed two aspects of recruitment. I stated in the participant information sheet that I would not share material from the research interview with anyone else. Secondly, the inclusion criterion was changed to include only prospective donors who had been assessed by the Clinical Psychologist and been given the go-ahead, that is, they were considered by the assessing psychologist to be at low risk of adverse psychological effects from donating. This did not mean that all participants would be going on to donate, since medical and personal issues could still intervene, but it meant that I could be reasonably certain that research participants would not be at greater than normal risk of psychological distress as a result of the research interview.

Had I not had this experience, I might not have felt as confident in the department’s internal processes and been reluctant to take such a definite line on

confidentiality. It served as a useful early lesson in the advantages and disadvantages of being a practitioner-researcher. It meant however that those prospective donors who were considered by the hospital psychologist to be unsuitable have been excluded from this piece of research, which has ethical implications of its own, and limits the availability of discursive repertoires for analysis. It is also an interesting example of the way in which discourses in the clinical and academic literature, which construct altruistic donation as a potential indicator of psychopathology, have impacted on the current study, providing an example of Foucault's notion of the way in which discourses constitute knowledge and power.

3.2.3. Participant recruitment procedure and data collection

Despite increasing year on year, the number of altruistic kidney donors in the UK remains very small. Altruistic donation is not publicised other than through media stories about donors and recipients, although information can be found on NHS websites. All participants in the current study had heard about altruistic donation through media reports and had approached the hospital directly or through their GP. The hospital is a regional specialist centre for kidney transplants.

I endeavoured to ensure that I was as distanced from the hospital as possible. All documents for participants had to be formatted in accordance with NHS guidelines found on the IRAS website and submitted for ethical approval. The approved recruitment procedure was as follows: After completing his own assessment of prospective donors, the consultant clinical psychologist asked them in person whether they would be willing to be contacted to take part in research being conducted by a trainee in the department. It was made clear that this would have no influence whatsoever on the individual's application to become a donor. If they agreed to be contacted, I sent a letter of invitation (Appendix D7) and participant information sheet (Appendix D8). I explicitly stated that I would not share any information with the hospital team and I put in place a framework for support in the event that the participant felt emotionally distressed after the interview in a debriefing document (Appendix D9).

Between July 2010 and July 2011, seven individuals who had approached the hospital with a request to become an altruistic donor and had been approved for donation by the assessing psychologist were written to with an invitation to take

part in the research. One person responded by telephone to decline participation, giving the reason that donation had been a private matter. Six responded either by telephone or email agreeing to take part. All participants were British, five were white and one Asian. There were five males and one female. Participants ranged in age from 41 to 63 years.

3.2.4. Pilot interviews

After City University ethics had been granted, two pilot interviews were conducted with prospective altruistic donors found through non-NHS sources. The intention in conducting pilot interviews was to refine both interview technique and the semi-structured interview schedule. The first pilot participant was identified through an Internet search using the term “altruistic kidney donation”. Results from this search yielded an anonymous donor’s blog, being written while the donor was in the process of being assessed for donation. A description of the current research and request for a pilot interview was sent and responded to by email. Informed consent was given and the interview took place at the participant’s home, lasting approximately one hour. A semi-structured interview schedule was used. After her interview, the participant suggested and emailed on my behalf another prospective female donor with whom she had been in contact, who was also taking part in an assessment process in another part of the country. The second hour-long pilot interview was also conducted at the participant’s home.

Pilot interviews were recorded on a digital audio recorder. I wrote field notes immediately after the interviews, recording my thoughts, feelings and initial ideas. I transcribed the interviews myself in order to become familiar with the text, and made further notes while I was while transcribing. Transcribed interviews were read and re-read several times. The interview text was interrogated for the effects it produced in me, including all thoughts, feelings and ideas. The interview text was then thematically coded to identify discourses that were considered relevant to the research questions and labelled on the transcript, following Willig’s (2008) first and second stages of Foucauldian discourse analysis.

3.2.5. Reflection on pilot work and changes to method

As outlined above, I was initially planning to use a form of Foucauldian discourse analysis for the analytic strategy in this study (eg. Parker, 1992; Willig, 2008).

However, on listening to and reading the first pilot interview, I became concerned that the semi-structured interview schedule that I had developed by drawing on the altruistic donor literature neglected emotional content in the interview. I was aware of the need to maintain a balance between finding a focus for the interview so that it did not become an unmanageable amount of text to analyse, and ensuring that the participant felt able to speak freely and productively but was unhappy that I seemed to be getting a largely factual account. I believed that I was getting the 'official' story, probably much as had been told to the psychologist involved in the assessment process.

I also found that at times during the pilot interviews, I wanted to interpret something of what participants may have been feeling. I reflected that this may have been a defensive protection of my own identity; that I may have been unconsciously feeling deskilled, which was leading me to try to demonstrate to the participant what a "good" researcher (and therapist) I was, but I also considered the possibility of whether in addition to this, the urge to interpret and ask the participant for an emotional interpretation of their accounts may have been telling me something about participants' defensive structures, as Walkerdine et al. (2001) suggest. I also considered whether the participants were talking to me from a particular discursive position, established in the process of assessment that they had already engaged with, that of proving themselves "sane" and rational. I wanted to know how we, the participant and I, could name and describe sensations, feelings, emotions, that they felt they had no words for. This is illustrated in this exchange with pilot participant Di (who has asked for her real name to be used) at the end of the interview:

Extract

JC: Is there anything I've asked you about that you felt wasn't relevant?

Di: I don't think so, no, it's just sometimes hard to explain why you think something, because if it's emotional based it's hard to explain, because you don't know where those emotions have come from.

JC: And it's hard to find the words to describe it.

Di: Yes, yeah, whereas if it's, I don't know, factual based, and I can't think of anything but, you can say well I did this because, you know.

JC: So it's almost as if having, I'm asking you to describe something that you have no words for, it's just something you know?

Di: Yes, it's just something I know.

(P001: Lines 1305-1318)

I decided that I did not know enough about the participant's biography, the trajectory of her life that had led to this point (Hollway & Jefferson, 2005). I wanted to think about the decision to donate a kidney to a stranger in terms of the donor's experience of subjectivity and their object relations. Importantly, the pilot work was taking place at the same time that I was beginning to specialise in a psychodynamic model of counselling psychology in my training, and illustrates the extent to which practice has informed this research. The conflict I was experiencing mirrored the tension I experienced in counselling practice, attempting to privilege the subjective experience of the participant whilst giving a theoretically informed reading of that experience.

Through Hollway & Jefferson's (2000) Free Association Narrative Interview method, I became interested in whether it was possible to interpret unconscious, possibly defensive aspects of the desire to donate from the text of an interview. However, this had ethical implications, as a social constructionist epistemological approach requires me to support the validity of participants' own accounts, not undermine them by imposing my own, theoretically-derived reading of them (Burr, 2003). I perceived a limit to the extent to which it was ethically acceptable to try to work with the theoretical idea of defensive motivations in research. Parker (2005) argues that attending to defence mechanisms is acceptable in critical psychology research only as a first step on the way to describing the social conditions that have elicited them in the individual.

Increasingly however, I was becoming concerned that in using Foucauldian Discourse Analysis alone, I risked neglecting a significant and interesting aspect of the decision, namely, the emotional aspects. Following the pilot interviews, I

was able to think more specifically about what I wanted to know. I wanted to explore whether it is possible to interpret possibly unconscious thoughts, feelings and behaviour that have somehow to be incorporated into institutional practices, with immediate implications for power relations. In this way, the study's methodology emerged out of a reflexive treatment of the pilot interview texts.

3.2.6. *Ethics of interviewing and interview procedure*

University premises were used for four of the six interviews. One was conducted at the participants' home (with measures put in place first to ensure my own safety) and the other at the participant's place of work in a private conference room. Interviews with participants lasted between 45 minutes and 75 minutes each. Confidentiality was explained and participants signed a consent form (Appendix D10). Interviews were recorded on a digital audio recorder.

In the ethical conduct of interviews, I have drawn on my experience as a counselling psychologist trainee whilst striving to remain mindful that research participants have not entered into a therapeutic relationship (Kvale, 2003). My intention has been to privilege the participants' account of their subjective experience, as Frosh & Saville-Young (2008) suggest. Kvale (2003) highlights the ethical differences between a therapeutic analytic interview and a research analytic interview, arguing that it is not appropriate to make interpretations intended to produce change in the participant. Nicholls (2009) describes a dilemma in interpretation from her own psychosocial study, concluding that when she did tentatively interpret to participants with the aim of clarifying understanding, it was generally useful and led to richer text.

The interview procedure was guided by the following aims: Frosh et al. (2003) suggest the interview produces an "illustrative narrative account" (p43). Hollway & Jefferson (2000) describe a biographical-narrative approach, and their "Free Association Narrative Interview" aims to explore the participant's relationship to the topic under scrutiny through focusing on the emotional content of the interview as a way of understanding an individual's meaning-making. They suggest four techniques of interviewing, borrowed from clinical interviewing, that are intended to allow the participant to produce "meaning-frames" (Hollway & Jefferson, 2000, p53). These are to use open questions; encourage stories; avoid asking "why" questions; follow participants' order of talking and use their phrases.

Walkerdine et al. (2001) also suggest a lightly structured interview that is aimed at eliciting a narrative that draws on both conscious and unconscious themes. Links are made by the participant through emotional means and interpreted by the researcher. This focus on emotionality in the interview is also advised by Frosh & Saville Young (2008) to enable access to subjectivity and meaning-making.

I used a semi-structured schedule as a guide (Appendix D11), departing from it in order to follow the participant's direction, picking up in a conversational manner on biographical aspects of their talk. Interview questions were drawn from my experience in the pilot interviews and reflected my interest in both social and psychological themes. This is in line with Frosh & Emerson (2005) who argue that personal biographical material and the participants' in-depth account of their own experience should be privileged for a psychosocial reading of an interview. Hollway (2008) also advocates that the participant's account should be "as unimpeded as possible" (p140).

I was informed by Kvale's (2003) "psychoanalytically-inspired academic interview" (p25). Questions included: Would you tell me something about your family? What was life like for you when you were growing up? Kvale (2003) argues that psychoanalytic relational thinking makes it a research method that is consistent with a social constructionist epistemology. Both are concerned with subjectivity, rather than the objective knowledge privileged by a positivist methodology. Participants' comments were clarified by asking about their own interpretation of their experience.

My first question was intended to orient the participant to the subject matter of the interview, their decision to try to become an altruistic donor. By using the phrase, "I'm interested in your decision to become an altruistic kidney donor, please tell me about it", I left the question open to interpretation by the participant, who was able to answer with whatever they felt to be most relevant. However, it should be recognised that even by using the word "altruistic" in my question, I was using a "pre-set theoretical concept" (Frosh & Emerson, 2005, p309). I took the description "altruistic kidney donation" from NHS literature. Frosh (2006) suggests that as we construct the stories about ourselves in order to make meaning of our experience, we are inevitably influenced by explanations of human nature that exist "out there", and this is one such instance of that.

Following Hollway & Jefferson (2000), I made brief notes during the participant's initial narration and tried to follow up these themes in their narrated order, taking care to use the same phrases and terminology. This interview technique highlights the inter-subjective nature of the approach and illustrates how the method inevitably leads to an explicitly co-constructed version of events. Stopford (2004) argues that participants should be given the opportunity to respond to the interpretive process. After this, I asked for biographical narratives, again in an open way.

The biographical focus of the interviews reflects Mitchell's (1988) description of the theory in relational psychoanalytic theory that intra-psychic phenomena are essentially developmental, resulting from childhood relational experiences. Some participants asked why I was interested in so much background information and I explained that I wanted to understand how their life experience and relationships might have contributed to their decision to donate. This response seemed to make sense to participants, who talked freely and generously. At the end of the interview participants were given debriefing information in which I gave my phone number and email address, as well as guidance about whom to contact in the event that the interview elicited distressing feelings that were felt to be unmanageable, including the participant's GP, Mind, and the Samaritans. Furthermore, as participants remained under the hospital's care while undergoing assessment for donation, they were able to contact their transplant coordinator, and/or the renal psychology department of the hospital should they need to. After the interview I emailed participants to thank them for their time and contribution to the research, again giving them an opportunity to comment on the process. None of the participants requested any support after the interview. All offered spontaneously to give follow-up interviews if it was required.

3.2.7. The ethics of a second interview

At certain points in the interviews, I noticed in myself a reluctance to ask the question: "What do you think is happening here?" I have used these moments in the second stage of the analysis, reflecting on what this might mean and drawing on the field notes that I wrote immediately after the interviews. Field notes focused on how I had experienced the participant and my thoughts and feelings about how they had experienced me at certain points in the interview. I reflected how at times, I felt uncomfortable asking questions that I imagined might be experienced

as difficult or intrusive by the participants. A clear example of this occurred in the first interview with the participant I have given the pseudonym “Richard”, when he described irreparable damage to the relationship with his mother earlier in his life. I chose at the time not to explore this at all and asked another question, effectively changing the subject. Afterwards I was puzzled and somewhat frustrated at my response. Frosh & Saville Young (2008) give a possible explanation of this, arguing that there are unconscious processes “likely” to be interacting in research work (p113).

A cautious approach to interpretation is considered ethical (Kvale, 2003), and I wanted to know whether a second interview might provide me with an ethical way to ask the difficult questions I was interested in. I reasoned that a second interview might enable me to explore and validate my interpretations of the emotional content of the interviews (Emerson & Frosh, 2004, 2009). However, I was aware of the ethical implications of a second interview and mindful that I had to take care to ensure that the relationship with participants did not shift from research to therapy. With this in mind, and after discussion with my supervisor, I decided that going back to participants would indeed risk shifting the relationship from that of research to therapy as well as suggesting that I did not “believe” what my participants had told me and wanted something more from them. In the information for participants I had included the possibility of a second interview, so I wrote via email to each participant explaining that I did not feel as though I needed to meet with them a second time and to give them the opportunity to they disagree with this and request a second meeting. All participants wrote back and were satisfied with having done one interview.

3.2.8 Field notes, transcription strategy and data handling

I wrote field notes as soon as possible after the interview, before transcribing. I borrowed from my counselling psychology practice in this reflexive exercise to note all feelings, thoughts and experience of the participant that the interview had elicited in me, with the aim of enriching my reading of the text through an awareness of my own contribution to the jointly constructed understanding of the topic. This effectively became the first analytic framework that I drew on, and drew on the same practice as reflexive work in therapeutic practice.

The transcription strategy was informed by social constructionist perspectives that emphasise co-construction in interviews (Emerson & Frosh, 2004/2009). Frosh & Emerson (2005) argue that transcription decisions both reveal theoretical assumptions and produce particular readings of the text. Transcripts were made anonymous and some identifying details were changed. As I transcribed and later listened to the interviews I made further field notes when struck by moments of potential emotionality. I drew on transcription conventions described by Atkinson & Heritage (1984) but omitted the more detailed techniques for transcription from Conversation Analysis. Transcription therefore included my questions and responses, false starts, pauses, laughs or evidence of sadness or distress (Frosh & Saville Young, 2008). Line numbers were added to transcripts of interviews. A number in square brackets in the text indicates a pause of a certain length. Eg: [4] indicates a 4 second pause.

Copies of transcripts and recordings were saved to CD-R disks and stored securely in a locked filing cabinet. A second copy of all the transcripts and recordings was stored securely at another location.

3.2.9. *Coding of interviews and analytic strategy*

Yardley (2008) suggests that in the pursuit of validity in qualitative research, it is necessary to provide a detailed description of how data was coded and how or whether codes were modified. Interviews were labelled with P and a number. P001 and P002 refer to pilot interviews. P003 through P008 are interviews that have been analysed. Pseudonyms were assigned to participants.

In this study I aimed to integrate several levels of analysis; a discourse analytic reading of the constructive nature of discourses together with a consideration of the emotional, biographically informed and situated investment that an individual has in these discourses. The aim of the discursive analysis was to identify how participants use discourses in the research interview to construct altruistic kidney donation and consequently the subject positions that are afforded to them and others by these discourses. Arribas-Ayllon and Walkerdine (2008) describe how Foucauldian discourses form relations between things, making objects “thinkable and governable” and importantly, how discourses can be resisted (p105). Interviews were first listened to and read in transcript form as Hollway (2008) suggests, and thematic notes were made on the right hand side of the transcripts.

For transparency, a section of an annotated interview transcript is included as an appendix (D12).

A Foucauldian approach to discourse analysis was carried out following Willig's (2008) six stages. Willig's (2008) method does not constitute a full discourse analysis but was considered to be sufficient for the aims of the current study with its focus on subjectivity. I was also informed by Parker's (1992) guide to discourse analysis, and Potter & Wetherell's (1987) discursive psychology approach.

Stage 1: All references to altruistic donation in the transcript were identified by physically highlighting the sections that contained any reference, even obliquely, to it (Willig, 2008). Wetherell (2005) refers to these "units of analysis" in the text as "psycho-discursive practices", arguing that individuals formulate and constitute notions of self, identity, emotions, motives, intentions and beliefs through them (p80).

Next, I made hand-written thematic notes on the right hand side of these highlighted sections of the transcript. These notes later aided grouping of discourses into themes. I extracted from the interview texts all references to altruistic donation and noted the interview line numbers. The following example shows my descriptions of discursive constructions of altruistic donation in Richard's interview (P004) as I made them:

<u>Reference to discursive construction</u>	<u>Line number</u>
A positive thing	5
A worthwhile thing to do	29
If I can do it, why not do it	30
Something that will make a huge difference to somebody	31
Something it would be "churlish" not to do	33
An obvious, natural thing to do	50
Part of being caring and considerate	640
Nothing special	642
Not something to make a big deal about	664
No reason not to do it	666
A very small risk	671
As something full of anticipation	707
Body as vehicle	768

Kidney may as well be used while it's still good	770
As something that will hopefully make a difference to somebody's life	772
Not about recognition	774
No loss to me	776
Maybe an unusual thing to do	784
Not particularly significant	785

Stage 2: I named the different discourses that were being used in the construction of altruistic donation (Willig, 2008) and then wrote descriptions of discourses that aimed to exhaustively incorporate all examples of discursive constructions for each participant, only stopping when all references to altruistic donation made by a participant could be described by a discourse. Examples of these included: helping discourses; biomedical discourses, risk discourses and self discourses. This process was cyclical, if a reference did not fit within an existing discourse, I created a new one to describe it (Wetherell & Potter, 1992). Through doing this, three overarching groups of discourses began to emerge. I found that by putting the discourses into groups in this way, I was able to begin the next stage of analysis.

Stage 3: For this stage I examined the "action orientation" of the discourse in the context of the research interview (Willig, 2008, p116). I asked what the participant was achieving by using this discourse at this point. Here it was necessary for me to interrogate how my interview questions led the participants to answer in particular ways. Wetherell (1998) advises that it is necessary to ask what discursive activities my questions key into. I also thought about how the function of the different discourses meant that they related to other discursive constructions in the text (Parker, 1992). For example, a medical discourse might be drawn on to demonstrate to the interviewer that the participant is knowledgeable and to shore up a less "rational" discourse that is emotional in content.

Stage 4: Thinking about the functions of discourses and their inter-relationships (Parker, 1992) enabled the suggestion of possible subject positions (Davies & Harré, 1990) afforded by the discourses to the donors and other individuals. Willig (2008) describes how "discourses make available ways-of-seeing and ways-of-being" (p113). For example, a medical discourse positions the donor as rational

and therefore in accord with the health professionals who control access to altruistic donation. This position therefore has important implications for power in the relationship between donors and health professionals. It makes it more likely that they will be allowed to donate. This demonstrates how the fourth stage links into the fifth stage of discourse analysis.

Stage 5: Next I considered how the discourses and associated subject positions related to practice; "...what can be said and done" (Willig, 2008, p117). Using the above example, if a donor chooses not to draw on a medical discourse and take up the position it affords, the donor is to a large extent positioning themselves as outside of the existing power structure and probably reduces the likelihood that they will be allowed to go ahead with donation. I found that this stage overlapped considerably with the final stage, possibly because what can be said and done depends to a large extent on an individual's subjective experience.

Stage 6: Willig (2008) suggests that this is the most "speculative" stage of analysis (p122), and I found this to be the case. The aim was to explore what the discourses used by the participants might have implied for their subjective experience: "...what *can* be felt, thought and experienced from within various subject positions" (Willig, 2008, p117, italics in original).

The six stages were repeated for each of the six participants. After analysing individual interviews, I looked for unifying and differing themes between them. Rosenwald (1988) argues that in attempting this synthesis, homogeneity of participants is not important and heterogeneity may be more productive.

3.2.10. Analysing participants' emotional investment in discourses and subject positions

Participants' personal investment in discourses were analysed, drawing on a psychosocial approach. Care was taken to ground the interpretations in what could be observed in the text (Frosh & Saville Young, 2008). This stage of the analysis was concerned with suggesting possible psychological explanations for the emotional investment that participants made in the discourses they have chosen to use. It was foremost a reflexive process, in which I drew on the biographical information available in the text, my own responses towards the participant during the interview and towards the recordings and the text. This level

of analysis was therefore informed by an interpretive strategy that attends to what Hollway (2008) describes as the “whole narrative” (p140), to include the meanings that are co-constructed between researcher and participant, links in the participant’s account, conflict, tension and what is not being said, as well as what is. Psychoanalytic theory and biographical detail contained in the interview was drawn on to provide a tentative interpretation of participants’ personal investment in the discourses they use, in line with Frosh & Saville Young (2008).

The intention was to provide as “bottom-up” as possible a reading of the text (Frosh & Emerson, 2005) while explicitly acknowledging what Burr (2003) describes as “the illusion of democratisation” in the research relationship (p156). Clarke (2008) recommends aiming for a subjective reading in the interpretation of text, attending to the parts where researcher and participant co-construct data. Frosh & Emerson (2005) advise a process of analysis “in which interpretations might be tested within the text itself, treating them as discursive constructions the effects of which can be examined and discussed” (p322).

I endeavoured to hold in mind the following questions: What are altruistic donors communicating about themselves at given points in the interview? How was meaning being constructed jointly by the participant and me in the interview? Particular samples of text to be subjected to a more detailed psychoanalytic reading were selected according to Gough’s (2004) description of emotionally-laden text “...where there seems to be a lot at stake, as signalled in talk by hesitations, exaggerations, evasions and emotive interjections” and times when talk is “...infused with anxiety and/or desire, where speakers passionately construct ‘others’ as threatening” (p247).

To summarise the analytic process, the two stages of analysis did not always proceed in the order described, but formed a cycle (Frosh & Saville Young, 2008). This began with my felt responses to the participant in the interview, which I recorded in my field notes, noting how the participant and their talk made me feel in the interview and immediately afterwards. After this, the focus of analysis moved to the text and recordings, and I continued to try to reflect on what was being evoked in me at the same time as thinking about what was being accomplished discursively. It was necessary to move flexibly between the different analytic frameworks, thinking about the wider social meaning of discourse, a

situated approach to discursive repertoires, and the feelings and thoughts that were being evoked in me by the text and the recordings.

3.2.11. *Validity and reliability*

Yardley (2008) suggests the following principles for demonstrating validity in qualitative research:

- i) It should be sensitive to context, including the relevant theoretical and empirical literature, the socio-cultural setting, ethical issues, the empirical data and the participants' perspectives. The analysis must not impose meanings on the data but allow them to emerge and be open to alternative interpretations.
- ii) There needs to be methodological competence and rigour in terms of data collection and analysis ought to be a rigorous and in-depth engagement with the topic.
- iii) The study needs to be coherent and demonstrate clarity and power in its argument. It ought to demonstrate a good fit between theory and method. Methods and data presentation must be transparent and subject to a process of reflexivity.
- iv) Consideration needs to be given to the impact and importance of the research in practical or applied, theoretical and socio-cultural terms.

Frosh & Baraitser (2008) suggest that using reflexivity to interpret inter-subjectivity in psychosocial research inevitably challenges traditional ideas of validity and reliability in research, and that from this perspective *all* knowledge necessarily has to be thought of as interpersonally and temporally determined. A discussion of validity in psychosocial research entails considering the constraints that are placed on interpretation by the methods employed. Habermas' (1971) hermeneutic approach means that in research, just as in psychoanalysis, only the participant can give validity to the researcher's account by their willingness to internalise interpretations as new knowledge about her or himself. This means

that interpretations made in research do not have the same status as those made in a therapeutic setting.

The psychoanalytic approach that I draw on both in my counselling psychology practice and this research does not attempt to interpret a description of a psychological structural reality in patients, clients or participants (Layton, 2008a). Instead it acknowledges and works with the idea that reality is continually reconstructed between subjects as it is enacted in relationships (eg. Safran, 2002). This is consistent with social constructionist and psychosocial research paradigms, which argue that the participant actively constructs meaning in the interview in relationship with the researcher (Frosh, 2006).

In psychosocial research, Frosh & Saville Young (2008) argue that a similar way to assessing a clinical interpretation, in terms of its capacity to produce a deeper emotional response in the client, may also be drawn on in this analytic approach to a text, to ask “what way of understanding generates most material, what pushes thinking on, what “thickens” the story that can be told about how psychological phenomena might work?” (p117). Although validity is necessarily limited in this approach to research, it can be increased through adopting a tentative stance towards the text and cautiously checking the interpretation with the “emotional tone” of the participants talk and the reactions of the researcher (Frosh & Saville Young, p117). Ultimately however, all that can be validly claimed is the intention to give an account of a “possible reality” (Frosh, 2006 p38).

3.2.12. *Summary*

In this chapter I have set out my understanding of a post-positivist, constructionist approach to the generation of knowledge from interpretation of other people’s subjective experience. I have described how the methodology of this study has been informed by social constructionist, Foucauldian, psycho-discursive and psychosocial research perspectives, and situated this in the discipline and ethics of Counselling Psychology as a pluralistic practice. The methods for text collection and analysis have been described and the ethical and reflexive aspects of the work have been explored.

D.4. ANALYSIS and DISCUSSION

4.1. Introduction and reminder of methodology

This chapter contains an analysis and discussion of the way in which discursive themes are used by participants in the research interview to construct altruistic kidney donation and position themselves and others, and explores the possible practice and subjective experiences that these discursive positions make available (Willig, 2008). The analysed text comes from semi-structured biographical narrative interviews with six individuals who volunteered to become “altruistic non-directed kidney donors” at a UK hospital during one twelve month period in 2010/11. I have drawn on the six-stage analytic strategy proposed by Willig (2008), together with the psycho-discursive approach to discourse analysis recommended by Wetherell & Potter (1992), Wetherell (1998) and Edley & Wetherell (2001). The study of a situated flow of discourse aims to engage with the “formation and negotiation of psychological states, identities and interactional and intersubjective events” (Wetherell, 1998, p405). The discursive object for the purpose of this analysis is “altruistic kidney donation” (Willig, 2008).

At the end of each section there is a psychoanalytically informed analysis of subject positions for one participant, three in total. The aim here is to use psychoanalytic interpretive strategies to broaden my thinking about the intra-psychic and inter-subjective aspects of altruistic donation as a way to theorise the “unconscious dimension of subjectivity” (Frost & Hoggett, 2008, p440).

Wetherell (2003) suggests putting socially constructed and intra-psychic theories “side by side in engagement with each other to see what we might learn” (p100), and that by applying a psychodynamic analysis alongside a discursive one, the person is treated as an additional site of meaning-making. In the previous chapter I outlined concerns about the “diagnostic” nature of some psychoanalytic thinking and its assumption of a psychic structure underpinning an individual’s reality (Frosh & Baraitser, 2008; Parker, 2005; Wetherell, 2003). One way to integrate epistemological differences between psychoanalysis and social constructionism is to draw on the relational aspects of psychoanalytic thinking. This approach characterizes the individual’s subjective experience as always co-constructed in relation to the subjectivity of another (Layton, 2008).

4.2. *Overview of discursive themes*

I have chosen to present the discursive themes in this analysis in three broad sections. These themes have been selected because they offer a coherent way of interpreting the discourses used by all six participants. Wetherell & Potter (1992) suggest that coherence is one way of assessing the usefulness of an analysis. Separating the discourses into themes in this way has aided a clearer approach to the possible function of particular discourses, the subject positions that they make available to participants and others (including myself) and the implications of these for practice (Willig, 2008).

Imposing a structure such as this on the text is inevitably artificial. With my analysis, I am not suggesting that there are no alternatives and there is nothing inevitable or fixed about the meanings I have attributed to particular discourses, they are simply possible constructions amongst the many that are available. In choosing to present the analysis in a certain way, I have necessarily had to neglect possible alternative meanings. This is reflected by Davies & Harré's (1990) notion of positioning in discourse that emphasises the dynamic notion of linguistic encounters and by Wetherell (1998), who argues that there is always plurality in the subject positions available to individuals through discourse.

The groups of discursive themes are not discrete; there is overlap between them with discourses from different groups being used by participants to position themselves in similar ways. All participants draw extensively on at least one of the discursive themes and some made use of all three. Altruistic donation is constructed throughout the interviews in contrasting and at times conflicting ways, reflecting what Gergen (2001) suggests about discourses being "open to continuous alteration as interaction progresses" (p249). Wetherell & Potter (1992) also suggest that in addition to coherence, discourse analysis ought to look for variability in interpretive repertoires, that is, the different ways of constructing events, people and processes. Whilst attempting to hold this in mind, I have felt that within the limited scope of this study, it has been important to try to avoid becoming lost in the multiplicity of meanings available for each discourse; "the infinite regress of possible interpretations" (Wetherell, 1998, p388).

The first group of discourses contains participants' ideas about altruism, emotions, ethics and morality, particularly the way that participants relate their subjective

experience of emotions to altruistic donation. An important distinction to make is that these discourses are *other-oriented* and fit well with Batson's (2011) description of altruistically oriented emotions that he includes under the umbrella term of "empathic concern" for other people (p11). These other-oriented discourses are the "way in" to altruistic donation for all the participants in this study. For example, they often describe an instantaneous feeling of being drawn to it in response to learning about the possibility of altruistic donation from a television, radio or newspaper item: "I just sat there going, that's incredible, that's absolutely amazing!" (James; Lines 17 – 18); "...and I don't know what it was but it just hit me that...it's such an interesting idea" (Peter; Lines 10 – 12); "[it] sounded like a positive thing and I thought, why not?" (Richard; Lines 5 – 7).

There is also a rescuing discourse that suggests omnipotence; "I could stop somebody being on a machine, I could give them their life back" (James; lines 38 – 40). Participants construct altruistic donation as morally right and selfless, for the benefit of another person and as something that will change the life of that person for the better, even prevent them from dying. The implications for power that reside in this discourse are unavoidable: "...a kidney can make a huge difference to a person's life" (Richard: Lines 31 -32); "I could make a difference to somebody else's life" (James; Lines 33- 34); "...[the kidney] could make such a big difference to someone else that desperately needs it so it's as simple as that really." (Liz; Lines 17 - 19). Making "a difference" is a common theme, suggesting one possible interpretation that the desire to donate may reflect an experience of having an unmet need in the donors themselves.

These discourses also incorporate the notion of personal sacrifice that can be found in religious and socio-cultural traditions that encourage helping others. "I suppose it's quite deeply ingrained isn't it, the thing that you should try and help other people to erm, have a better quality of life if you can" (Liz; lines 113 – 115). They also sometimes evoke the idea of a higher order; community, fatedness, destiny and submitting to a force outside the individual's control, something like a calling; "...the Gods were saying you should do this" (James; lines 683 – 4), possibly thereby absolving the individual of some of the responsibility for taking the decision.

Importantly, these other-oriented discourses were drawn on by participants to describe ideas that they themselves found "obvious", as though the feelings,

thoughts or beliefs that they incorporated needed no explanation: “the right thing to do” (James, lines 784), “the right reasons” (Will; lines 355 - 6); “an obvious, natural thing to do” (Richard; Lines 50 -1). Using the word “right” suggests that there is no need to question the naturalness of these feelings, instantly setting the participants up in resistance to those who might suggest doubt. These discourses of certainty and obviousness foreclose on the possibility of ambivalence.

When it was suggested to participants during interviews that their instantaneous response to the idea of altruistic donation seems to have been driven by feelings, they tended to turn to rational discourses. It was as though they heard the question as suggesting that emotions were not a sufficiently well thought out argument, or perhaps were insufficiently rational. They were perhaps wary of sounding “mad”. Setting up emotions in opposition to rational thought reflects a Kantian view of morality and supports Blum’s (1980) argument that the Kantian approach is deeply ingrained in western moral thinking. I suggest that by using both emotional and rational discursive themes, participants are able to position themselves as both ethical *and* responsible when they perceive that their motivation is being questioned.

The second group therefore contains these rational, logical discourses about risk. It was the easiest discursive category to identify and code in the transcripts and includes discourses of risk, science, medicine, utility, engineering and the body. All participants used them extensively. Physical risks and discomfort are de-emphasised; “I’ve been a blood donor and regularly, and to me it actually doesn’t seem terribly different to that,” (Liz, lines 12 -14); “...nothing really to worry about” (Will; line 225); “If I don’t, I’ve let someone die for no reason” (George; line 117). These discourses allow the construction of a pragmatic, positivist stance. They serve to position the participants as rational, responsible individuals and crucially, enable them to resist accusations of psychopathology from experts and of ‘being crazy’ from medical professionals, friends, relatives and researchers.

However, an alternative way to think about these altruistic discourses of the body becomes possible with a focus on the way participants use them to emphasise the separateness of the physical self from the psychological self, a form of Cartesian dualism, dismissing the significance of the body, even possibly disowning it: “...it

seemed to me a waste to put it in the ground, if it can be used” (Richard; lines 49 - 50); “...re-use the bits if you can” (Will; lines 25 – 26). This way of talking disavows corporeality. There is no sense of a wish to keep the body intact and the donation of organs after death (“in the ground”) appears to be given equal status to donation while alive. I argue that this says something about the speaker’s feelings about their own aliveness. Perhaps this construction of altruistic donation allows for the possibility of the avoidance of mortality and loss. In saving the life of another person, the participants are in some way able to rhetorically defy their own embodiment and therefore eventual physical demise.

Lastly, I present and discuss a third discursive theme that is clearly evident in two participants’ accounts and only tentatively present in the others. This finding supports the value of negative case analysis in qualitative research (Henwood & Pidgeon, 1992). It is a psychological discourse of the self in which altruistic donation is constructed as something that can benefit the donor in emotional terms. Donation is “something really significant...something you could hang your hat on” (James; lines 179 – 182) implying an expected increase in self-esteem. In contrast with the first discursive theme, these discourses are *self-oriented* and as such they question definitions of altruism that assume no benefit to the donor: “...if it works, it will make such a difference to someone who’s really struggling, and...it does give me great pleasure, yeah (Liz: lines 107 -110); “So you feel good in yourself of having done something like this, which is probably why I’m doing it” (Peter; lines 134 – 145).

D.4.3. Other-oriented discourses – Emotions, empathy and self-sacrifice

4.3.1. Resisting questions

As might have been expected, all participants drew on moral, ethical and emotional discourses when they were asked to talk about donation. In using these discourses participants construct altruistic donation as an act through which they are putting another’s interests before their own. The rhetorical effect of doing this in conversation is to draw attention to the speaker’s moral or ethical position in a way that emphasises their empathic understanding of other people’s needs. Making the needs of others important in this way is consistent with contemporary psychological discourses of altruism, such as Batson’s (2011) empathy-altruism

hypothesis. Participants tended to use these discourses to construct altruistic donation as obvious and unremarkable.

Extract 1

JC: So can you tell me a bit more about that moment that you heard about it on the radio and you had the feeling that you would be interested in doing that, can you just give me a bit more detail about possibly went through your mind then?

Richard: Erm, I know, it, it...it's a thing that worthwhile doing and its er, erm, you know, I can do, why not do, you know if I've got two kidneys and a kidney I know can make a huge difference to a person's life, er, why not, it, it seemed, seemed er, churlish not to, you know, why hold on to it if I don't need it, just you know it sparked a thought I mean, er, ma-, maybe, it's part of my erm, personality that I, I, I, I, used to always donate blood since I was a teenager I guess... and I've also signed er documentation that my body should be used for, for, erm, science, or, student er, er, cutting up or whatever you know because again it seemed to me a waste to put it in the ground, if it can be used and so it just seemed an obvious natural thing to do when I, when I heard it was possible.

(Lines 25 – 51)

Richard's own needs are dramatically minimised through his altruistic discourses. He is suggesting that wanting to keep both of his kidneys when someone else is in need of just one of them would be positively selfish, even rude; 'churlish' as he says. On the other hand, the fact that he is referring to one of his internal organs generates in me, the listener, a sense of unformed anxiety. Why is Richard not entitled to "hold on to" his own body? He also seems to be suggesting that everybody who chooses not to give away a kidney is being "churlish". Yet there is ambivalence in his answer, "why not do it?" It is as though Richard experiences a sense of obligation to effectively sacrifice a part of himself to a sick stranger. This is a sense of responsibility that goes far beyond what the majority of individuals presumably feel.

A discourse of obligation such as this is difficult to contest. It positions the speaker on an ethical "high ground", in effect silencing argument. Discourses that draw on

the “obviousness” of the morality of helping another person in need reduces the listener to little more than an admiring observer, without recourse to argument or challenge such is the ethical weight of these discourses in philosophical and religious traditions. How does one argue with such goodness?

In his interview Richard described how he had experienced in his life a great many events over which he had had no control but which had had a powerful emotional impact on him, such as his parents’ and later his own divorce. This led me to ask whether he made any link between the idea of difficult things happening to him and his desire to help other people. I was thinking here about the idea of agency and finding compensation for a non-agentic life in compassion for others. However, this represents an intrusion of psychoanalytic discourse, because it reflects the idea that altruism is a defensive reaction-formation. Although I was attempting not to phrase the question in a way that Richard might have experienced as prescriptive, it is perhaps inevitable that he would have heard me making this link.

Extract 2

JC: *I’m wondering if you have any theories about how your experience throughout life has made you think about other people and made you want to, you talked about being very compassionate towards your family’s maid, and you talked about finding the apartheid system very, very disturbing and I wonder if there’s something about how you see other people, how you think about other people?*

Richard: *I, I, I, don’t know why my attitude is the way it is, it seems to me just normal and natural to be caring and considerate of others, in, in small things and in big things, er, er, I ca-, don’t know that there’s anything special about it, you know, giving blood it seems like erm obvious thing, you know you’re producing it all the time, you, you, you give a pint of blood it’s made up again in no time, it was in America that I started giving blood, erm, but what brought me to it I don’t know but it was convenient, I, I worked er, from where I worked in new york a few blocks away there was a place where you did it and er it seemed silly not to, you know [laughing slightly].*

JC: And is the kidney then just a continuation of that thought process?

Richard: I think so and also, the bone marrow is, is, I turned [inaudible] I was surprised when I found out, its apparently similar to giving well, blood, they just draw it out with big syringes, it's not, not, it's a bit more of a deal than giving blood but you know [intake of breath] again, you, you make it up a, again, I, I was, when I found out then I, as I say, I tried to do that too, the kidney, you know she [woman on radio talking about living kidney donation] made it sound easy and natural and not a problem and...

(Lines 632 – 659)

Richard argues that it's "silly" not to give something if you are able and suggests that he does not believe that the way he feels is "special", again taking up a position of resistance against my questions. By focusing on blood and then bone marrow donation and the "obviousness" of these, he resists talking about the links with his life that I have asked him about. He suggests that living kidney donation is more or less the same as blood and bone marrow donation. His laughter underscores his bemusement that it could be thought of otherwise. In all of this, he resolutely ignores my question about whether or not he thinks that his giving is rooted in some form of reparation, resisting this interpretation, describing it instead in terms of a discourse of pragmatism and utilitarianism.

He wonders whether helping people is part of his "personality". This psychological discourse describes his experience of wanting to help another person as something fixed and internal. All the participants felt as though being a helpful person is intrinsic to them as individuals, and it is also useful to consider that the principle of helping others is a common cultural ideal enshrined in all the major religions (Blum, 1980) and therefore constitutes a powerful social norm. That participants choose to respond to this culturally prescribed standard through living organ donation is nevertheless interesting, particularly when there are so many other opportunities to help which are arguably more effective in terms of the numbers of people who can be "saved".

I suggest that there is a potential for conflict for some participants (although not all) when discourses of being a "helping" person are compared with their feelings

(or lack of them) of valuing themselves. Richard dismisses the idea that his own life holds any intrinsic value such as when he says, "...you know, you just happen" (Line 56). The moral philosopher Thomas Nagel (1979) remarks that a utilitarian ethical position such as Richard's, with its insistence on personal pursuit of the common good is demanding because the individual is not allowed to take up any "special position" (p203). One effect of utilitarianism is to deny a person's subjectivity through privileging the objective in any situation (Nagel, 1979). To deny one's own subjective importance is in practice a position of self-sacrifice. Through this discursive repertoire Richard seems to be saying: "I have no greater importance to myself than a stranger does to me". To his friends and family, it is possible that this attitude may be disturbing. As a discourse, it is quite aggressive in its rejection of being valued.

4.3.2. *Positioning other people in opposition*

All the participants spoke of how close friends and family were often opposed to them donating. It is possible that the other-oriented discourses the participants draw on have the effect of enraging or frightening the people who are closest to them, resulting not in an experience of admiration and praise, but criticism and persecution. James was bewildered by his parents' response, having already fantasised that he would gain their approval: James: "*I thought they'd be 'ah, isn't that a great thing to do, wow, we must have brought him up correctly', mm, well they didn't.*" (Lines 130 – 132)

In response to strong criticism from his sister, constructed by her in terms of protecting their parents from distress, in his interview, James gives an account of himself as an emotional yet still rational individual who is motivated to become an altruistic donor in order to "give something back" for the many privileges he says that he has experienced in his life. This enables him to take up the ethical position and identity of a "good person" (versus his sister, who is necessarily positioned as "bad"). In extract 3 below, he accomplishes this position discursively with contrasting positions; by downplaying the effort that it requires on his part whilst describing it at the same time as a "massive thing to do" that he thought about "every breathing moment". James draws on these two contrasting constructions of altruistic donation when he relates the story of having to withdraw because his parents were worried about him.

Extract 3

JC: Tell me, so what your, what was your perception of how they felt about it?

James: Erm, they, from what my sister said, they said that it was the chance that I could die, it was nothing to do with the other person who'd be getting it, it was the chance that why would I put myself through something that could kill me, and I didn't get that. I said, "Don't you think I've been through this with the doctors, over and over again, where they've ad nauseum told me these are the risks, these are the risks", and my sister said, "Oh they're lying, they're lying, it's much worse than that, I've looked on the internet"; [sighs] "You know I'd rather not look on the Internet and I have looked on the Internet anyway and it agreed with what they [the doctors] said, so I'm not sure what you're looking at". But she's probably fed them [their parents] with all this stuff, of, "he hasn't thought of this and he hasn't thought of that", when every breathing moment from the time that I saw that news story, to the moment I ended up having to say I couldn't do it, was, I was just thinking about it the whole time. It was such a massive thing and I honestly think I had thought of everything, and I knew the risks, and they seemed not, minimal, but worth it, worth it.

(Lines 134 – 154)

In extract 3, James answers my question about what he perceived his parents believed by reporting a conversation with his sister. He seems to be angry at the suggestion that his parents may value him more than they do a stranger, drawing on both altruistic and risk discourses to strengthen his argument. They ought to be thinking about the recipient, he is saying, and in any case, the risk of harm coming to him is low. Then, as if this discounting of the facts was not insulting enough, he says that his sister will probably have undermined his reputation for being able to make a rational decision. Disembodied speech communicates his feelings of bewilderment and indignation at having to defend himself from the accusation of irresponsibility from his sister, suggesting that he has heard my question as asking for him to account for himself. He condemns his sister using her own words. His feelings come very close to the surface and I am faced with his considerable anger and hurt feelings. His emphasis functions to convince me, his questioner, of his deeply heartfelt commitment to donation, to ensure that in spite of his having had to pull out, I understand unequivocally that he did not do it out of

choice. By using an emotional discourse in this way James takes the subject position of an ethical person who wants to show that he cannot comprehend why his sister might criticize him for his actions, which through their very nature ought to be regarded as selfless.

James thereby positions himself as resistant to criticism – in response to the criticism that he has experienced from his sister. This may also be the way that he experienced me in the interview. His talk positions him as “good”, and his sister as “bad” for preventing him from going through with the donation. Importantly, it may also function to prevent me from questioning him further, as if the morality of donation is so obvious there is really no need for us to examine it more closely. In this way James accounts for wanting to be an altruistic donor by using emotional discourses to underscore and provide additional evidence of his (already established) rational, intellectually sound commitment to the process (Edwards, 2001). I, on the other hand, am positioned by this discourse as another possible doubter (and therefore less moral) because I, like his sister, have questioned his motives.

Finally, in spite of his earlier rational discourse surrounding risk assessment, James can also be heard to construct the absence of evidence against altruistic donation as something that makes it in some way fated for him, or pre-ordained: *“The gods were saying ‘you should do this or we would have thrown up a reason why you can’t do it’”* (Lines 683 – 686). The function of this dramatic discourse may be to absolve him, perhaps in relation to his sister’s accusation of selfishness. It places him in a position where responsibility for the decision to donate is now out of his hands and with it the pain that he has, albeit unintentionally, caused his parents (and himself). This might help him to avoid experiencing the difficult emotions that are associated with this particular chapter of his life, to put an end to both internal and external debates. If he has no need to question it further himself, the implication is that others, myself included, need not do so either.

There is talk in all of the interviews describing how it is other people in the donors’ lives that have problematized the morality of altruistic donation. In light of this, it’s possible that participants experienced me as also problematizing their decision through the fact of doing this research. One way to think about this is to consider the ways in which other people might experience participants’ discourses of

empathy and physical sacrifice as discomforting, leading them to oppose the altruistic donation. The discomfort is presented in the socially acceptable terms of caring for the donor's wellbeing, of not wanting them to put themselves at risk for a stranger, a "reason" that is often rejected by the participants.

Extract 4

JC: What's your interpretation of that, why do you think they were so negative?

George: I would like to think that they were looking out for me, but I think that would be, I don't think that would be the case in most instances. I think they were just, they thought it was a silly thing to do.
(Lines 106 – 111)

All of the participants described incidents in which they had been criticised fiercely by friends or family, of how they had been urged to reconsider the donation, and how surprised they had felt. The attempt by other people to prevent the donor from going ahead places them in the confusing and uncomfortable position of having to defend something that they had constructed for themselves as obviously moral and logical.

Extract 5

JC: So it was this, I guess like you say, why not, this kind of, it seems very logical to you...

Liz: Yeah, mm, it does.

JC: Because you can do it, erm, but it's not, that's not the response that everyone having that, reading that article [about altruistic donation] would have had.

Liz: No, absolutely, and what's been quite surprising to me, the most surprising thing about the whole thing is that, is the reaction of people when I tell them. Now at first I sort of thought, no, I'm not going to mention it to anyone, I'll keep it quiet until I'm definitely going to do it. Then I started telling friends and I would say 80% of friends say that I'm mad, erm, and er, some of them are quite vocal about it and think it's completely the

wrong thing to do, and you're messing with nature, and if, you wouldn't have two kidneys if you didn't need two kidneys, and what if your children need them, and what if you fall off your scooter and you need one, and, and, I, it's definitely about 80/20 against, from the people that I talk to...
(Lines 31 – 48)

George described how he encountered a similar reaction and also, like Liz, how “surprised” he had been at the reaction.

Extract 6

JC: Tell me about that, what that was like and what sort of reactions you got?

George: I was incredibly surprised, everyone, every time I saw them raised it and sort of stated their, erm, dislike for that.

JC: They were against you doing it?

George: Absolutely. I mean not just 'oh that's really stupid, you shouldn't do that', [but] 'You're mad', they would make a very big point of it...

(Lines 82 – 90)

The uncomprehending and confrontational stance from friends and family reflects discourses in the academic literature, which frequently takes as its starting point the possibility of psychopathology in the altruistic donor. James believed that his sister had “stoked the fire” with their parents because “...*she didn't like the idea that I was going and doing something that she would never be able to do*” (lines 288 – 292), constructing donation as sibling rivalry. I am suggesting that there is something about this particular altruistic act that generates anxiety in other people that is then turned against the donor. It is possible that altruistic donation induces uncomfortable feelings in those close to the donor. Social pressure to conform to behavioural norms thereby reduces the chances of a person behaving in an altruistic way by creating conflict in the donor, as happened to James.

This seems to be what Judith Butler (2005) is saying, when she describes how Foucault argues that relating to the self is always a social action and is therefore regulated by social norms. Butler (2005) suggests that if it is indeed the case that

“socially enforced modes of individualism” force us to be “narcissistic”, preventing “self-acceptance or forgiveness” (pp135-6), then it is important for us to engage with Foucault’s idea of there being a price to be paid for social constructions of the self, or making meaning for the self through social constructions. It may be that in the case of the altruistic donors, they pay that price through the internal conflict that is generated by the disparity between the way they have chosen to construct themselves as a helping person, and the way society, in the form of their friends, family, doctors and psychologists, attempt to enforce individualism upon them. In conducting the research interview, I too have put participants in the position of having to defend their actions, to justify what they feel should be “obvious” and that what they are doing is an unquestionably “good” thing. Donors discursively seek to solve this dilemma that they find themselves in by positioning their family and friends as “selfish” in comparison. This can be seen in Liz’s interview. This extract continues from her earlier statement of surprise at the negative reactions of others, given above.

Extract 7

Liz: “...I’m not, I don’t mean to be judgmental at all, but I bet they don’t give blood either, you know they will, they will take it, when they need it after an operation or an accident but I guess there’s a kind of person that does those things, and doesn’t really think twice about it and, and I guess I’m one of those people. But I’m quite surprised by how vociferous people have been. (Lines 49 – 55)

Like Richard earlier, Liz appears to be taking the position that we are all morally obliged to help people in need if we are able; it is the ‘default’ position, what you do if you are a good, thinking person, she seems to be saying. But again this has difficult implications for anyone who does not choose to act this way, because the only subject position this automatically affords others (including me) is a selfish one. George was clear and damning of his friends’ response: “*I think they’re selfish and greedy*” (line 133).

Another way that donors respond to perceived criticism is by keeping their decision secret. This has the added benefit of being consistent with a discourse of altruism, in that it is constructed as for the sole benefit of another person. It makes discursive sense for the donors to be seen to avoid attention of any kind. This is

likely to impact on their feelings about the research interview, making them feel uncomfortable and even more likely to refute the possibility of personal gain.

Extract 8

JC: Um, did she, did you tell her [Will's mother] about your altruistic donation?

Will: Yes I did.

JC: What did she think?

Will: She was a little bit non-committal and um, er, I didn't tell anybody else, I, I kept it quite a closely guarded secret so I wanted to do it for the right reasons, if you start telling people it's like, you know, I'm being a hero, I'm going to donate a kidney, la-di-da-di-da, but I didn't want to give that impression at all, do it for the right reasons and um, just don't tell anybody, but I told my mum."

(Lines 351 – 359)

Will uses the fact that he kept his plan secret from everyone other than his mother as evidence of the rightness of his intentions, offering it to me as proof that his altruistic motivation is genuine. Modesty is a discursive resource that allows him to construct donation as being genuinely about another person and not himself. This enables him to protect himself from perceived attack by potential critics. If donors don't tell anybody about what they are planning to do, they cannot be criticised or forced into reflection on what they are doing or why they want to be altruistic donors, and through not seeking attention or reward for their action, they are able to remain entirely within a "pure" altruistic discursive construction. Thus the avoidance of attention, conveniently consistent with dominant socio-cultural expectations of altruistic behaviour can also be a way of avoiding external and/or internal criticism in the context both of the research interview and in life outside. This external pressure on the altruistic donor to conform to social norms through an enforced consideration of their own and the needs of those closest to them is consistent with Layton's (2009) critique of the neo-liberal discourse that she argues is dominant both in our society and in the psychological therapy room. The effect of this discourse, argues Layton (2009), is that we are all encouraged to separate psychic and social influences to the extent that we believe that as individuals we are responsible only for the happiness and wellbeing of ourselves

and of those closest to us, not the individuals who make up society at large. Altruistic donors do not fit this model, which may explain why they seem to generate feelings of anxiety and resistance in other people.

From Layton's (2009) perspective, in acknowledging the suffering of a stranger through their actions and choosing to involve themselves in it, altruistic donors are making themselves vulnerable to another's situation in a way that does not fit with a neo-liberal discourse that discounts empathy and altruistic discourses in favour of more hedonistic theories of motivation. In making themselves vulnerable, donors encounter resistance from close family and experts who might be argued to be drawing on a more mainstream neo-liberal discourse. At this point, altruistic discourses become a circular argument, enabling donors to position themselves at the summit of a moral hierarchy. The donor is able to refute the criticism of others, making themselves in some sense inviolable. I tentatively argue that they may then go a step further, and link what they are doing to their own identity and constructions of self, absolving themselves from having to reflexively question their decision.

Extract 9

Liz: I guess there's a kind of person who does those things and doesn't really think twice about it and I guess I'm one of those people.

(Lines 52 – 3)

Liz compares herself favourably to her critical friends, who are not *like* her; "I bet they don't give blood either" (line 50). By making her altruistic donation central to her identity in the context of the research interview, Liz is able to ignore her friends' protests and go ahead with her plan to become a donor. In this way, helping discourses that at first seem to privilege the other also give Liz and the other donors the opportunity to demonstrate agency and control in their own lives.

4.3.3. Constructing relationships and positioning the recipients

Despite the emotional tone of the discourses used by donors, altruistic donation is notable for the absence of actual emotional ties with the recipients. Donors have chosen to participate in a method of helping in which anonymity is assumed. A discourse of altruism thereby enables the donor to position themselves as good and ethical whilst, somewhat paradoxically, remaining *outside* any emotional

attachment with the person they are helping. In this distal relationship, participants actively empathised with the recipients to a varying extent. A discourse of empathy was most evident from the only female donor in the study, Liz. The separation from the person being helped is highlighted by the contrast implied in Liz's referral to the people with whom she has had the closest emotional relationship with, her two adult daughters, when she explains why she has chosen this point in her life to become an altruistic donor. The anonymity of altruistic donation seems to present a stark contrast with the her twenty years of parenting:

Extract 10

JC: OK, and so why this point in your life, do you think?

Liz: My two daughters...they're big enough to look after me if I need them, er, but I guess, I've been a single parent for twenty years, and I guess I kind of feel that they're now old enough to erm, er, certainly to look after themselves if I'm incapacitated for a while, er and I guess it's kind of yeah, it's kind of my time really, I think.

(Lines 85 -94)

Being a parent, and perhaps especially a "single parent", as Liz describes herself, is likely to be an intensely emotional role. It suggests a relationship in which feelings of responsibility are magnified due to the absence of a second person with whom to share the emotional and practical work (and the rewards) of parenting. Now that Liz's children have grown up, instead of relinquishing a caring role, she has chosen to help somebody with whom she has no connection whatsoever. Altruistic donation appears to be constructed by Liz here as a reward to herself, something that she has earned through twenty years of parenting.

Altruistic donation is a solitary act, enabling her to ignore the protestations of her friends and help a silent, presumably grateful and largely invisible second party. From this perspective, altruistic donation offers the donor a strikingly different type of relationship from the intense, messy, complicated reality of being somebody's parent, son, daughter, husband or wife. For Liz, her construction of altruistic donation may be a way of actively distancing herself from those closest to her, and in this sense it might be said to free her, cutting the family ties that have bound her and giving her a form of independence after years of caring.

All of the potential that social relationships have for infiltrating and affecting the psychological and the personal, the way that we are unavoidably affected by the people we are in relationships with, can it seems, be avoided in altruistic donation. The recipient can remain an abstract, not a real person. It might even be suggested that the donor holds all the power in this particular relationship. As James said, "I could stop somebody being on a machine, I could give them their life back" (lines 39 - 40). It is paradoxical that by doing something so morally "right" and also so physically intimate, the donor is able to avoid being in a reciprocal relationship. Will particularly did not want to think about the participants at all when he was asked about them. He gave a very clear reason for this; to avoid being hurt in the event that the recipient was not grateful.

Extract 11

JC: Do you think about that person it might help?

Will: Erm, no I try not to, I, um, in case they don't say thank you.

JC: What would that be like if they didn't?

Will: If they knew and they just um, they just um, it's like doing a favour for somebody and then, like my sister, you know, I've seen her in plays, she's never come to see me doing anything and um I don't want to experience that. "There's the kidney, I hope it goes well for you", that's all.

JC: So if you think about them and try and sort of imagine them in anyway then they don't thank you, you would experience that as quite hurtful?

Will: Well I'd be very hurt and it's um, a bit of a big thing isn't it?

JC: Yes, it's a very big thing.

Will: And er, if I knew who they were and they knew who I was and they didn't say "thank you mate", or just ignored it or just, I don't want to go [there], I don't want to experience that. They can have the kidney but I don't want to know who they are, job done and I'll never know.

JC: And then you won't have to be disappointed?

Will: And I don't get the opportunity of being disappointed, there you go.

(Lines 605 – 621)

Will risks making himself vulnerable to what feels like despair through donation; *"I don't want to go [there]...I don't want to experience that"*. He imagines that if he is not thanked for donating his kidney, being ignored and "disappointed" will be more painful than he can bear. It is therefore much safer for him emotionally to avoid thinking about the recipient at all. He links this feeling to the way he experiences his sister as uninterested in him. He feels ignored in their relationship, despite believing that he is engaging with her. Will seems to long for the love and admiration that he feels is absent in his relationships yet has chosen a way of relating that involves a stranger and the option of remaining anonymous. This extract, and Will's investment in it will be considered in greater detail below (p165).

Throughout the interviews, potential recipients are positioned by participants' discourses as sometimes central to the decision, but at times as secondary to it. Recipients are however unavoidably the subject of this action and are positioned in these discourses as helpless, disempowered through disease and dependent on the donor for their health, maybe even their life. This subject position is an inevitable consequence of discourses that construct the donor as 'saviour'.

James, who had to pull out of donating a week before his scheduled operation after his sister told him that his parents were concerned for his safety, was deeply distressed by thoughts of the recipient and said that he tried not to think about the person. The competing discourses of altruism that he and his sister were using placed James in a highly confusing, possibly even unbearable position. His sister has accused him of being selfish, irresponsible and stupid using the very act that he constructed as entirely selfless, and now he is being asked in the interview to experience anew the painful feelings. James appeared to be upset and angry at this stage of the conversation, understandably so.

Extract 12

JC: Is it a lo-, is it that it brings up feelings of loss for you about not having been able to do it?

James: Loss, and anger with my sister when I think you know she's my only sibling and when my mum and dad go she'll be the only one left and I can't believe that she would do something like that, that I thought was selfish, she was calling me selfish and I couldn't believe that she was doing that. How can I be being selfish here, I'm not doing this for me, I'm doing it for somebody else, I will get this lovely feeling, I've been told that, but, and she honestly thought I was doing it for myself. 'You really don't know me very well do you?' (Lines 565 – 576)

It feels as though his anger is directed at me in this response, as though I am the one who has misunderstood and misrepresented him; “*You really don't know me very well do you?*” is a direct form of speech. James has taken the opportunity of the research interview to construct his decision to pull out of donating in a way that allows him to make sense of his conflicting emotions. One way to avoid his sister's accusation of selfishness is to position her as less ethical than he is; “she would never dream of doing anything like this” (line 287). This enables him to maintain his own positive identity even though he has had to withdraw from donating. In contrast with a risk discourse, with which he downplays his investment, here he again constructs donation as a significant emotional event to such a degree that being asked by me to think about the fact that he has had to withdraw makes him feel uncomfortable. The *uncaring* position he is placed in through this discourse, and the discomfort he experiences in recounting this experience to me is difficult for us both and the reason for this becomes clearer when he describes how he has resisted thinking about it until now.

Extract 13

JC: ... What it's like talk-, I mean I know it's uncomfortable talking about the conversation with your sister, is there any other, are there any other feelings around this whole thing for you that we haven't talked about?

James: I don't like to think about the guy who was getting it. That's something I managed to completely blank out I think. God there was somebody who was told we've found a match, he was given a date and his family were all round him there, wow, next Tuesday, whoa, here we go, so that's something I don't like to think about. [5] No, I, I know it's weird, but that is what I've done now, I have managed to just blank it out because there didn't seem any, didn't see any point, there's no

advantage to going over it and over it and getting annoyed, so I just haven't really thought about it. There was a series on TV not long afterwards, specifically about donors and everything, and they were showing people going through the operation and everything, and it was just, I couldn't really watch it, excuse me [coughs], I couldn't really watch it because it was just too, oh no, I could have been that person and that person...who was getting it, he could have been that person, yuk.

J: It felt yuk, it felt horrible to think that you could have been the person doing that.

P: Yeah.

J: It seems like you really identified, you'd already really identified strongly in some way, you'd already sort of thought ahead and put yourself in the position of what it would be like to have done it.

P: Yes, I think going through all the tests and everything and speaking to the doctors and, you have to do I can't remember, is it one or two psychological evaluations, so they ask you, they make you think about this sort of thing. [coughs] so yeah, so it was the biggest thing in my life and I thought about it all day, every day. (Lines 662 – 696)

My question about his having “identified” with being a donor was intended to reflect my sense that he had internalised a particular idea of himself, and to try to convey my understanding of how difficult it must have been for him to have had to let go of this identity. The two subject positions that his discourses make available, one as a good, ethical person, providing the opportunity for a positive subjective experience, and the other offering failure, pain and guilt, add up to the likelihood of him feeling highly ambivalent about the research interview.

In contrast, the absence of a clear image of the prospective recipients in participants' discourses, and the absence of curiosity expressed by some is striking, positioning the recipients not just as invisible, but not even permitted to be thought about other than in the most general sense. It is possible that the recipient and their suffering can be avoided to some extent in this way.

Extract 14

JC: You mentioned about the person whose life you could have saved a little while ago and what are your sort of thoughts and feelings and ideas about the person, whoever they are, that might get it?

George: I assumed that I would never know who they were.

JC: No. Do you have any particular ideas about people with kidney disease, dialysis; is there anything around kidneys specifically that you [inaudible]?

George: No because I was asking about what else I can give, [laughs] sorry I was. I was saying you could have a bit of my liver if you want, you can have bits of this or that. I don't have, I've never known anyone on dialysis or anything to my knowledge, erm, I do know people that only have one kidney through motor accidents or whatever, not many but I know a couple and they've had no problem, erm, No, I mean, it was just to help someone out. I don't know, maybe I'm sitting at home by myself too much, you see these things and think well at least I'm getting out of the house for a bit, I don't know [coughs]. (Lines 166 – 184)

George says that he is prepared to give away *any* bit of himself and says that he is not interested in who will get them. Although his discourse is verging on the sacrificial he makes light of this, laughing, wondering whether it is because he is “sitting at home by myself too much”. He uses humour to minimise the emotional significance of what he’s doing, undermining his own importance in the process; “it was just to help someone out” feels like something of a deliberate understatement in this context. Perhaps in reaction to my question about the person whose life might be “saved”, it is possible that George’s outwardly unconcerned attitude is due to modesty or even embarrassment, that my question feels grandiose to him. Yet it seems unlikely that an individual who does not want attention would volunteer to have an operation in the course of which they will receive the attention of a great many people. It is not just the recipient who is strikingly absent from this discourse, George himself is also missing, in the sense of an ‘I’. It is possible that he experiences what he is proposing to do as something that he feels *cannot* be explained, at least in any way that is consciously available to him.

D.4.4. Emotional Investment in Discourses - Richard

The story of Richard's childhood and later, his own marriage, can be read as one of parental omnipotence and Richard's own powerlessness in the face of it. In his account, his childhood was dominated by things happening to him – major events brought about by his parents – over which he had no influence, yet which would have had a profound effect on his own experience. His parents divorced when he was a young boy, and as Richard says in the interview, there was “nothing he could do about it”, and he “admired” (perhaps idealized) his mother for bringing up the children alone. When Richard and his twin sister were seven, their mother wanted to take them out of the country but their father refused to let them leave, so Richard, his sister and an older brother went to live in a children's home for a year. They saw their father twice a week, a situation that Richard said was “ok”, and how his father remained “devoted” to them.

On his mother's return she married again and the children went to live with her and their new stepfather. For reasons that were unclear, Richard's stepfather objected to them continuing to see their own father and a plan was concocted in which Richard and his sister, at the age of “nine or ten”, were instructed to tell their father, in the presence of a lawyer, that they did not want to see him any more. At the last minute, Richard says that he refused to go through with the act and later continued to see his father in secret. His twin sister did meet her father as she had been instructed and bore the brunt of this dreadful experience, according to Richard, becoming unable to walk for several months with a medically un-diagnosable condition that Richard told me he now assumes was “psychological”.

JC: So I'm trying in my mind to get a picture together of this life which has been eventful, your life has been full of change and relationships ending and beginning and, adaptability, a huge amount of adaptability on your part, having to adapt to new situations.

Richard: “Someone pointed out to me once that er, there'd been erm, a, a, few erm serious points in my life where it changed dramatically without me having any control over it, erm, I hadn't thought about it until that was mentioned, and maybe that's one of the reasons why I

feel fatalistic about life I don't know and I also feel, I, I, I'm not a person of power or of aggression or of self-assertion, erm, but you know first of all my, my parents divorced when I was small and I remember th-, how, that there was nothing I could do about it, but it was a great pain, then my erm mother married my stepfather without, before she even came to say hello I'm back from the united states, you know she married my stepfather with whom we didn't have a good relationship even before, I, we knew him as a teacher before, erm, [pause] and er then my wife, er, erm, er getting involved with somebody else er, without me knowing anything about it, I of course, again couldn't do anything about it, erm, [pause] but er, anyway." (Lines 599 – 621)

One of the most striking aspects of the interview with Richard and his discourses about altruistic donation was his absolute determination to refuse to give himself any special status above that of the stranger who would have his kidney. He drew on ethical and biomedical discourses of morality and risk but resolutely rejected discourses of the self and would not accept that what he was proposing to do was in any way remarkable, as if making himself special in any way was unthinkable. To decide to give someone the “gift of life”, yet argue that this is not something remarkable, seems at times to be perverse. It is as though he is unable to experience himself as special or deserving of praise in any way.

In extract 1, above, Richard says that once he found out about the possibility of altruistic donation, it seemed “churlish” not to do this “obvious, natural thing”, comparing it to giving blood, which most would not consider it equivalent to, in either medical, personal or ethical terms. Understanding the compulsive quality of this is where the psychoanalytic notion of the unconscious may be useful. With his use of “churlish”, he seems to be saying that because he *can* save a life, he *must* do so. His determination and compulsion on learning of the possibility of altruistic donation is marked, as when he described how he “immediately made an inquiry” and “eventually” managed to get information after “multiple attempts”. It is as though he is compelled to make a sacrifice of himself through his foreclosing on his own value. Altruistic donation is something he does for no personal gain; in the interview, he refuses to allow himself to take any pleasure from his giving. It seems that donation is not a loving act, but rather one that repeats his experience of deprivation.

Richard's emotional investment in the discourses he uses suggests that he does not care what happens to himself, such as when he asks; "why not?" become an altruistic donor. He is ambivalent, but in a negative way, as though he is not able to care one way or the other what happens to him. In his interview, I experienced Richard as reluctant to talk much about being altruistic. He insisted that donating was merely a function of his "fatalistic view of life" (line 56). Through his construction of altruistic donation as something that *ought* not to confer a special self-status, he denied the possibility of any related personal loss, needs, importance or intrinsic value, saying; "...if I were to die on the operating table it wouldn't make any difference to me" (lines 678 – 679). By giving a part of himself away and not being concerned about the possibility of any negative outcome for himself, he splits himself from his physical body. It seems from this as though Richard feels that for him, living and dying are equivalent.

Richard's lack of ability to care for himself can be seen in the discourses he uses to think about whose life is valued more, in which he positions the prospective recipient of his kidney as worthy of being saved while his own life is relatively unimportant. It can be argued that Richard has made an emotional investment in this discursive categorization of self and other (Wetherell, 2003). In the interview, Richard avoids a claim for personal significance through altruistic donation, although he recognizes that at certain times in his life things have happened to him over which he has had no control, he chooses not to see his altruism in light of this.

Richard's discourses of altruism in the interview can therefore be interpreted in several ways; as full of humility and concern for the other, or as an aggressive rejection of the self and others. He resists a discourse of reparation as he describes himself as "...*in some ways a bit of a waste of space*" (line 756), and "...*one of the many...not one of the few*" (line 781). He feels that his parts are inter-changeable with others, that he is not special or unique. He has no intrinsic value. Being with Richard felt sad, unsurprisingly.

Richard's strict ethical position allows him to continue to experience his own lack of specialness and his account of not wanting children is consistent with this refusal to even consider his own needs:

“I regard having children as a supremely selfish act, that you don’t give children [life]... that, that life isn’t a gift, that life is a sentence, that for one’s own, er need to have something to love or need to erm, to, er, erm, live eternally, you have a child to, who does that for you, but it’s, it’s for your gratification that you have a child and er, you know, the child has to suffer life, to satisfy that need in the parent”. (Lines 511 – 518)

Richard seems to be saying that his own unhappy experience of childhood felt like “a sentence”. With a psychoanalytic reading, it is possible to suggest that Richard’s subjective experience of wanting to be an altruistic donor symbolises unconscious feelings about himself as an object and his experience of being powerless in his own life. Altruistic donation may therefore offer him a way to manage the sadness that he feels about his failure to make something more of his life.

D.4.5. Rational Discourses

4.5.1. Responding to criticism

In the previous section, a discussion of ethical, altruistic and emotional discourses was presented in which the participants constructed altruistic donation as 'obvious'. All participants said that donating altruistically was not something they considered themselves extraordinary for wanting to do. Using this discursive resource, they seem to be suggesting that there is little or no need for further examination of their decision. However, when they were asked to account for their decision in the research interview there was a tendency for participants to draw on alternative rational and actuarial discourses. With these discourses, participants reported factual information and hard data, consistent with the medico-legal notion of informed consent that is found in official literature for altruistic donors.

Participants also describe the physical costs of donation as relatively insignificant. By downplaying the physical risks and by making this argument, they are able to position themselves as rational, logical individuals.

In a Kantian approach to morality, the question of how to live a good life, or living ethically through putting others before the self is an act of humanity, but it must be a rational as opposed to an emotionally driven process (Blum, 1980). This is consistent with the way clinical judgments about organ donation are made, founded on the principle of the unacceptability of harm to the donor ("*first do no harm*") balanced with the prospective gains for the recipient (Beauchamp & Childress, 2001).

These contrasting discursive resources, one "emotional" and one "rational" appear to be in conflict. Parker (1992) describes how contrasting discourses can overlap to construct the same object in different ways. The fight between these competing discourses can be seen in this extract from James's interview in his response to a question about the role of emotions in his decision:

Extract 15

JC: It seems as though it was almost like an emotional response rather than a, actually kind of reasoned response.

James: Mm, bit of both.

JC: You were sort of feeling...

James: I couldn't think of a good reason why not, you know, I was quite happy if somebody had then turned round and said 'you haven't thought of this James', but they didn't... (Lines 44 – 50)

Having spoken previously in the interview using emotion discourses, at this point James switches to a risk discourse in response to my question about feelings. This allows him to resist my interpretation. He replies to my second question, “you were sort of *feeling*...” with; “I couldn't *think* of a good reason...” He is resisting my agenda, which is to get him to talk more about the feelings that he described earlier, and his resistance takes the form of his rational discourse and positioning. Perhaps he hears my question about feelings as a suggestion that he has not properly thought about what he is doing, just as his sister did, and so he provides what he considers to be a more intellectually rigorous account of himself. He cannot think of “a *reason* not to do it” (line 31), there can be “no excuses” for someone in his position (line 169 -170), a person with no partner or children who depend on him. These are all very cognitive responses, and from this discursive position he attempts to reduce the emotional significance of donating, describing the operation as just “a bit of discomfort, and a bit of time out of your life” (lines 40 – 41) and it's “nothing” (line 40).

Through this pragmatic discourse, James constructs altruistic donation as a low-risk activity and in doing so positions himself as a mature, sensible individual who demonstrates competence at assessing risk and uses the same language as clinicians. With this discursive repertoire he may be warning me not to go on trying to position him as emotional and therefore by extension “irrational”. He describes having sought out and examined the evidence as an autonomous individual who is capable of finding and evaluating evidence using a methodical, scientific approach. Unfortunately for James, this approach was ultimately not successful in his attempts to convince his family of what he wanted to do.

An actuarial or risk discourse can be argued to provide participants with a response to perceived questioning or criticism of their action by others, positioning the donor as “sane” and “rational” as opposed to emotional and “irrational”. What is more, it is difficult to dispute and can be readily backed up with references to medical and organ transplant regulatory literature, and can be used either to

augment, or in place of, the emotional and moral discourses discussed above. In contrast, detractors are positioned as “irrational”, and in George’s case, he delivers a further rhetorical blow by arguing that this also makes his critics “selfish and greedy”.

Extract 16

JC: You feel selfish and greedy for your friends who want you not to do it?

George: I think they’re selfish and greedy, I don’t think that, I mean, I don’t know, maybe my perception of life is very different and weird, I just think well I’m fifty, if I gave a kidney away tomorrow and in twelve months time I had problems with the one that I had left which ended up resulting in me dying, I know this sounds probably a little bit depressing but I did what I could with the information that I had at the time. I don’t think I’m particularly, erm, scared of death, I don’t want it to be painful or anything but I don’t want to die either, but I don’t know, maybe I’m just a little bit too pragmatic for my own good, I don’t know.

JC: Yeah, I was thinking about, as you were talking then, how, I wonder how much you value your own physical body, yourself?

George: It does sound like that. When I went and saw the psychiatrist at the hospital and I was saying I want to do this and do that and he was sort of looking at me, yes, I know it sounds stupid, everyone’s told me it sounds stupid, and he went down the same [inaudible], and I said “No, I want to live until I’m 180 I think, I mean there’s things I want to do, places I want to go, there is just no time left, yes I want to do things but everyone’s got to die, there’s no point in, I don’t know, when it happens it happens. I don’t want to bring on my own death but, walking across the road could do that, I’ve got better, actually I’ve got a better chance of giving a kidney away than technically walking across the road and getting hit by the number 10 bus”, so yeah. (Lines 131 – 162)

In this extract, George appears to be suggesting that for him, dying as a result of donating would be an acceptable outcome. Talk about death is frequent in this extract and throughout George’s interview mortality discourses recur. He suggests that he is simply “pragmatic” about death and dying, but like his earlier talk about

altruistic donation being “just to help someone out” (line 182), the repeated use of “I don’t know” suggests the presence of doubt. He seems to be taking a logic discourse to its extreme and it is not clear what the function of this discourse might be for him in terms of his subjective experience. It is true that in medical terms, the risk of permanent harm being caused to a kidney donor is considered to be low. But arguing that the chance of harm from donation is “acceptably” low is surely not the same as arguing that death would be an acceptable outcome, which is what George appears to be saying in this extract.

This apparently uncaring attitude to his own life or death, in order to improve the health of a stranger, is what prompted my question about whether he valued himself. In his response, he recounts what he had already told the assessing psychologist at the hospital, using a fatalistic discourse “everybody’s got to die”, and the enigmatic “there is just no time left”, as well as a more “rational” risk discourse that constructs altruistic donation in terms of probability. If, as George argues, death “happens when it happens” for him, why the attempt to stop it happening to somebody else?

Liz also chose to “rationalise out” her decision and used risk discourses in her response to those of her friends who told her she was “crazy” for wanting to donate.

Extract 17

Liz: ...everything that they [her friends] talked about, er, you know whether it was the er, erm, the fact that you, do you need both kidneys, what happens if your children need them, what happens, you know all of these things I can rationalise out myself and still think, I’m gonna do it, you know, there’s a good reason to do it, the chances of that happening are so small, that erm, it’s not a good enough reason not to do it, in my mind.

(Lines 72 – 79)

Discourses of utility, that position the donor as possessing a useful commodity than can be put to use for the greater social good, are also commonly drawn on to fulfill the same function. To the listener, this discourse can feel cold and clinical, which is disconcerting and evokes anxiety. This was certainly my experience. Something of a similar feeling of anxiety is provoked by Richard’s admittedly rational yet nonetheless disquieting discourse in which he creates for himself a

subject position of being indifferent to his own continuing existence, similar to that evoked by George in the extract above.

Extract 18

JC: The risk doesn't bother you? I know it's a very small risk in statistical terms.

Richard: Yeah, it, it, it's a very small risk and er it doesn't bother me. If it bothered my children it would be an issue and that's why I've discussed it with them and I've tried to make clear to them what the risk is, er, and they're both intelligent sensitive people and they're [inaudible], they, they seemed, they, they are quite happy with it, I've kept them abreast of all the checks that I've had and so forth and they've not expressed any reservations at all, and that's what matters, if, if erm, if I were to die on the operating table it wouldn't make any difference to me, it might make a difference to them, you know, it er, so, yeah, no, I'm not, [intake of breath] I'm not concerned about the risk. (Lines 669 – 681)

Richard's apparently cavalier attitude to his own mortality, "if I were to die on the operating table", is, like George's, somewhat shocking, especially in the context of *saving* lives. The idea that death "wouldn't make any difference" to him suggests that he does not value his own life as much as he values the life of the prospective recipient of the kidney. It seems, if not suicidal, then indifferent to life. From a clinical perspective, this does not fit with official discourses of altruistic kidney donation, which strongly emphasise that the donor should not be put at risk of significant levels of harm in order to donate to a stranger.

Richard and George seem to be almost embarrassed by the attention of the research interview. This leaves me feeling somewhat nonplussed as the listener, it is disorientating to experience and I don't know where to go next. Both construct altruistic donation as *not* heroic, and *not* emotionally important. George explicitly dismisses any emotional investment on his part in donation, using a discourse of logic in its place

Extract 19

George: I'm no bloody hero, I don't know, it's just a logical decision.

JC: Logical?

George: Well for me yes, I think so, it is a logical decision, it's not, I think I probably made it logically, maybe I never made the decision emotionally I don't know. I've never really attached any emotion to the decision. Again, maybe if I had have given away a kidney, maybe after the event the emotion would have hit me, I don't know, but I've never really attached any great emotion to it. I've got two healthy ones, you can have one, the chances of anything happening to me that are bad are remote so. (Lines 723 - 734)

When George is pressed to think about what altruistic donation *is*, rather than only what it is not; the constructions that he chooses are those afforded by logical and risk discourses. I have wondered whether after facing so much criticism from his friends, might he be expecting criticism from me as well?

From the perspective of the participants' subjective experience, in addition to the positioning of themselves as "sane", the use of discourses associated with rationalism might also enable them to avoid, or get rid of some their own potentially uncomfortable feelings about what they doing, preventing (or 'defending against') the experience of distressing emotions and anxiety. Peter acknowledges the paradox of not being on the donor register and explicitly refers to the possibility of his own avoidance in the interview when he questions his use of these discourses, wondering whether he has underestimated the potential for harm involved in kidney donation or whether; "...is it that you actually don't care?" He moves between using the first and third person pronouns, splitting himself into interviewer and interviewee potentially pre-empting questions that may be difficult to hear.

Extract 20

JC: Have you done other medical altruistic, do you give blood for instance?

Peter: No, no, you'd think you'd start off and you'd think that you have some involvement with kidney patients through some connection with that side, but I have no, there's nothing like that. It's not that I, I haven't even filled out a donor card, you know, you'd think there's a progressive step and this is the sort of ultimate sort of thing, it hasn't followed that so even when I, in talking to you now, I think you know why is this happening and why are you doing it and if you stopped and thought about it and you just, is it that you actually don't care? You know, if something happens to you, oh so what.

JC: Is that what it feels like?

Peter: Well I'm just thinking that there might be some element of that but I do care, you know, and if God forbid something happened to me, you know, how would that impact on my children and those that are close to me, would there be an unnecessary thing to risk your life for, you know, do I not care enough about them to expose myself to the risk? I've thought about that absolutely. I probably perceive the risk to be possibly less than it is, I'm not, it doesn't concern me. (Lines: 83 – 103)

Peter asks himself whether his apparent lack of emotional investment is evidence of the fact that he doesn't care about himself and by extension, and more disturbingly for him, his children. He dismisses this idea almost immediately when he examines the feelings more closely and realises that he cares very much that his children do not lose their father. It might be that Peter experiences caring about his children as more acceptable than caring about his own welfare. In response to my question asking him to clarify his feelings, "Is that what it feels like?" he draws on a risk discourse that enables him to extract himself from the uncomfortable position of not caring about what happens to him. As with Richard, by constructing altruistic donation in such a way as to suggest that he does not care if he is harmed in the process, Peter's discourse conflicts with the medical principle of the donor not coming to harm, and it is possible that he realises this in the course of the interview and alters his position to fit with a more "acceptable" discourse of altruistic donation. Later, he revises his position by referring to his attitude towards medical procedures, this time constructing it as an operation that carries with it an acceptable level of risk, reinforcing the idea that he is in no real danger of coming to harm or of his children losing their father. He chooses

however not to respond to my question about the significance of giving away a part of himself, turning again to a medical discourse with which he can distance himself from the personal aspect of donating.

Extract 21

JC: We've talked about a little, we've talked a bit about the idea that it doesn't feel like a very big deal to you but I just wanted to quickly pick up on that idea, that your body and how you feel about the fact that you're giving away a bit of your body, does that have resonance for you?

Peter: It really doesn't impact on me in terms of, you know, there's going to be an operation, some element of risk in it, I know that I'll still be able to function quite normally afterwards, people do it every day. I don't have a fear of medical things so it's not, it really isn't a big deal.

(Lines 492 – 501)

Compared with the other participants, Peter makes greater use of the research interview to reflexively explore the idea that altruistic donation might be a symbolic action. He is able to observe himself from a third position (Britton, 1988). In the interview, he can be heard to be actively constructing and deconstructing donation and at times seems to contradict himself. An example of this occurs when at first he describes his reasons for wanting to donate in order to feel good about himself, to prove that he has value, and later in the interview when he says that he's doing it to be helpful to another person. I experienced these contradictions as confusing and at times difficult to follow. In contrast, the other participants appear to be more certain of their views, more concrete in their thinking, and the detailed risk discourses they use to construct altruistic donation may function to provide them with a socially acceptable subjective experience of altruistic donation.

I have argued that rational discourses might be used in interviews because they allow participants a socially acceptable way to account for the complex emotions that accompany the decision to become an altruistic donor, and which are possibly not available for them to put into words. This construction of donation as low risk is intended to allay anxiety not just in themselves but also in other people. Peter suggests this interpretation of the use of a risk discourse himself:

Extract 22

Peter: I'm not sure whether it's because of my desire to do this deed is overpowering and somehow diminishing the "what if", I might be too dismissive of that because my desire to let's say, well to put it bluntly, make myself feel better for what I'm doing is so overpowering that I may be too dismissive of the dangers, but I've tried to be objective about that.

(Lines 515 – 521)

4.5.2. Engineering discourses - managing feelings about death and dying

Richard situates his decision to donate in a pragmatic, bodily discourse. His body is constructed as a commodity to be used efficiently, not "wasted" in death. The implication is that if the body is no more than the sum of its parts, subjectively for Richard there is no need for him to have any feelings about what he is proposing to do. He effectively resists questions about motives in this way.

Extract 23

Richard: I've also signed documentation that my body should be used for, for, erm, science, or, student er, er, cutting up or whatever you know because again it seemed to me a waste to put it in the ground, if it can be used and so it just seemed an obvious natural thing to do when I, when I heard it was possible. (Lines 46 – 51)

Will's interview is particularly notable for the way in which he constructs altruistic donation by integrating engineering metaphors as a "solution" to emotion problems. In response to my first interview question, he described how he had been going through a "bad patch":

Extract 24

Will: ...and I thought about taking my own life and um, I thought, well, I'm going to make sure, you know, I can be broken for spares. You know, being a good engineer, you know, you reuse the bits if you can. (Lines 23 – 26)

Will's phrases; "broken for spares" and "re-use the bits" are starkly mechanical discourses in the context of mental distress. On discovering however that suicide would mean that his organs would be unsuitable for transplant, he made a bargain

with his GP, in return for an appointment with a psychologist to find out “what’s wrong with me” (line 28), he offered to donate a kidney to a stranger.

Extract 25

JC: So you’d made this promise, erm, still it was, it’s quite a big thing to go through with, I’m just really wondering what that, why the commitment to this particular way of helping people?

Will: Um, well, as I say, if I had have killed myself um, it would have been a shocking waste of some good bits and I’ve been healthy all my life, and I mistakenly thought you could have the lot. (Lines 95 – 100)

...

JC: But that came out of a rather dark period of time where you felt that you probably didn’t want to go on living anymore, is that right?

Will: That’s true, yes, although the realisation it was a shocking waste of, a shocking waste of um, you know, body parts was when I read about those suicides, I thought you know, why not, you know, didn’t you carry an organ donor card or something like that. Little did I realise it didn’t matter because, you know, you’ve done it, you know, they can’t get the parts, I didn’t realise that at the time but years later when, you know, I did think about taking my own life, but then I thought well, you know, have a live, be a live donor. (Lines 586 – 593)

Will as a ‘self’ or an ‘I’ seems not to exist in this extract. There is no suggestion that it would be a shame or sad for him that his life had come to an end, merely the problem of the waste of “bits” and “parts”. The reduction of himself to “parts” is a discourse of bodies as commodities, foregrounding the physical, embodied person and positioning the symbolic aspects of self, the things that make us who we are psychologically, not just as unimportant but non-existent. “I am nothing more than my body”, he seems to be suggesting. It may be significant that Will made his decision to become an altruistic donor when he was experiencing psychological distress. One possible subjective experience of this focusing on the physical, material aspects of his existence is that his mind and the pain it causes can be neutralised. I suggest that the function of these engineering discourses might be to enable Will to think and speak about his experience of psychological

distress, along with the potentially disturbing subjects of death and dying, in a way that he can tolerate. He also may assume that his listener will be better able to tolerate this way of thinking. It is a way of approaching what may be a very frightening idea in a manageable way, promising an escape both from continued, painful existence, as well as from annihilation, through a form of recycling, a way of going on living after death.

Will also drew on logistical discourses and these seemed to serve a similar function as the engineering repertoires. In response to a question about his feelings around the assessment process at the hospital, he constructs altruistic donation as a logistical problem to be solved, thereby again affording himself a position that is largely free of possibly troubling emotions.

Extract 26

JC: And as you were going through that [the assessments], can you remember what your feelings were about it? Did you start to get a sense of anticipation about what you were doing, or can you describe for me how you were feeling as you went through this, as it would have appeared to be getting closer?

Will: Um, [8] I think just sort of, that erm, kind of just want to get it over and done with, you know, it's [4] yeah, it's just go up and, for the assessment and um, er, you're just like let's get it over and done with but I suppose the other thing is like where can I fit this in? You know, it's a fairly big thing I'd better be out of work for about a month, um, probably two weeks off, maybe part time thereafter for a couple of weeks, you know, your body takes a bit of a knock and Christmas is the best time and then, yeah, that's sort of it really, it's kind of like planning, like planning when it's going to happen.

JC: Mm, so it was a logistical exercise to some extent?

Will: Yes.

JC: And in terms of thinking about how you would feel about yourself afterwards, did you have any, was there anything there?

Will: Er, not really, no.

(Lines 198 – 215)

Although my question to Will was about the *feelings* that were evoked by being assessed, his answer is punctuated by two long pauses and he is not prepared to enter into an emotional dialogue with me here. He is resolute in his matter-of-factness, constructing altruistic donation as a chore that has to be planned, or a task that he wants to “get over and done with”. He is not willing to consider the possibilities for feelings about the aftermath of donation here, refusing to be drawn, but sounding far from convinced.

4.5.3. *Medical discourses – absolving responsibility.*

Participants also use medical discourses to allow them to feel safe and secure in the expertise of doctors and the NHS. These experts are positioned as knowledgeable and competent to make clinical decisions, they are handed power willingly in this situation. Will describes how he put himself in the hands of the medical profession without doing any extra research.

Extract 27

JC: It seems as though it was quite a straightforward decision for you then, it didn't hold much emotional or anything particularly difficult, any difficult feelings for you or any particularly strong feelings for you, would that be right to say?

Will: No, no worry as such, you know, I'm fairly confident in the health service, I've seen people on the TV, you know they, and I met, as I say I've met these two recipients and they're fine and the people who've donated a kidney they're fine as well, so nothing really to worry about there. Erm [4] erm [3] yes, no real medical worry, no, but it's a little bit of anticipation or a little bit of, you know, it is quite something there, you know, the er, and a little bit of worry about there's a small risk that you might die. I think it's one in er, they told me, one in er three thousand, but I think life's risky and um, so I thought, right I'll make a will...”

(Lines 218 – 230)

Will's talk is much more hesitant here than the transcript suggests. There are pauses of four and three seconds respectively, and frequent use of “er”, suggesting that Will's subjective experience may extend beyond what he is overtly expressing. It is possible that he is using medical discourses to convince himself and others of the low risk. If there is no significant risk, he need not think much

more about it. And if he does think about it, then the response is once again strikingly practical and logical; "...right I'll make a will".

James describes a similar seemingly blind trust in medical expertise when his sister suggests that the doctors "just want your kidney", saying; "*I really do trust the doctors, they're not going to do something that's wrong.*" (Lines 62 – 64)

Liz is also very clear that she expects the operation to be medically straightforward and cites this as being central to her decision. However, she seems the most prepared to think about the realities of the operation itself, in addition to which she has had the opportunity to link the expectation of the pain involved to the type she experienced when giving birth, which she constructs as a positive type of pain, different from being ill or injured, and which she draws on here:

Extract 28

Liz: ...if it was a really long drawn out painful er recovery, I may not do it, you know, I love the fact that that we're probably looking at something now that has been quite well perfected, that is a good technique, that is less invasive, that it makes the recovery period so much shorter and I think that's something that I can cope with you know, I have quite a good attitude to pain, erm, and I don't think it will be too much of a problem, particularly because you know where the pain's coming from, it's a bit like childbirth, you know, because I'm, I'm not ill. (Lines 322 – 332)

In summary, all the participants constructed altruistic donation as a low-risk, rational decision, drawing on medical, engineering and utility discourses in which they positioned their bodies as commodities that ought not to be wasted. This includes those participants who had also talked about it in emotional terms. I have argued that the effect of these discourses is that participants foreground their physical selves at the expense of their psychological selves. These discourses may therefore function to provide a response to critics who suggest that donors are "crazy" to want to give away a kidney to a stranger, by displaying evidence of rationality and knowledge. I am also suggesting that these discourses may provide participants with a manageable way to subjectively experience thoughts and feelings relating to the anxiety-provoking experience of psychological distress, physical pain and mortality.

Additionally, it is important to note that the discourses in this group represent not just the views or feelings of the donors. Of all the discourses drawn on by participants, this group corresponds most closely with discourses used by experts and in the official literature and so are most likely to receive approval from the expert position. By positioning doctors and medical professionals as benevolent, objective and scientific, the use of a medical discourse enables donors to align themselves with some of the power that resides in the medical establishment.

D.4.6. Emotional Investment in Discourses: Will

The interview with Will was notable for his determined use of engineering and mechanical discourses. Unlike the other participants, who tended to turn to these types of discourse after they had described the emotional draw of helping someone in need, Will was unique for the fact that these discourses were all that he used.

In extract 24, he describes how as he was considering suicide, he was thinking about how his body might be most effectively put to use, thereby rhetorically avoiding the emotional implications of the end of his life as himself. There is a feeling of donation offering him something like a resurrection; the 'good' bits, which are his physical body are kept and recycled, while the 'bad' bits, his mind, can be killed off.

For Will, in extract 25, the waste of a person's body when they commit suicide is "shocking" – the sadness or otherwise that a person has chosen to end their life is not remarked on other than in these terms. Perhaps with these discourses, he is letting me know that he experiences his own life as something of a 'waste', that his 'good things' have not been properly used. In extract 26, he focuses on the practicalities of "getting [the operation] over and done with". He claims not to have any thoughts about what he may feel after having donated. He seems unable, or perhaps unwilling, to allow himself to feel anything about donating other than in terms of getting the job done.

In Will's narrative of his life, there is little evidence of any good relationships other than with his father, an engineer, who died suddenly when Will was seven, and with whom he said he was "good friends" (line 299). Will describes how he thinks his mother probably had not wanted another child after his two older siblings and how his childhood was not a happy one after the death of his father. His older brother is admired, a success in contrast with Will's failures, but the younger brother's love for the older is unrequited, and he feels that his sister is critical of him and selfish, unappreciative and refusing to recognize the interest he feels that he has dutifully shown her. His experience of his family has therefore overwhelmingly been one in which he is rejected, not seen for who he is. The romantic relationships in his life have been "total disasters" (line 461) with women "who have either been desperate or stupid" (line 466) as

though they are the only women that would be able to tolerate him. He says: "I've only got myself to blame most of the time" (line 569).

Seen from this context, in which every relationship he has had since his father died seems to have been a disappointment to Will, it makes more sense that Will would defend himself against the recipient of his kidney similarly disappointing him by avoiding becoming emotionally involved. The idea that the recipient might not be grateful to him, in the way that he experiences his sister as ungrateful when he is brotherly towards her, is almost too painful for Will to contemplate as can be seen in the following extract:

JC: *Do you think about that person it might help?*

Will: *Erm, no I try not to, I, um, in case they don't say thank you.*

JC: *What would that be like if they didn't?*

Will: *If they knew and they just um, they just um, it's like doing a favour for somebody and then, like my sister, you know, I've seen her in plays, she's never come to see me doing anything and um I don't want to experience that. There's the kidney, I hope it goes well for you, that's all.*

JC: *So if you think about them and try and sort of imagine them in anyway then they don't thank you, you would experience that as quite hurtful?*

Will: *Well I'd be very hurt and it's um, a bit of a big thing isn't it?*

JC: *Yes, it's a very big thing.*

Will: *And er, if I knew who they were and they knew who I was and they didn't thank you mate, or just ignored it or just, I don't want to go, I don't want to experience that. They can have the kidney but I don't want to know who they are, job done and I'll never know.*

JC: *And then you won't have to be disappointed?*

Will: *And I don't get the opportunity of being disappointed, there you go.*

Lines 605 – 621

It seems as though in spite of the fact that he studiously avoids the use of emotional discourses, Will is determined to go ahead with donation, is in fact deeply committed to it. He says; "I think it's a worthwhile thing to do and it could help somebody enormously" (lines 603 – 4). This remains an extremely pragmatic discourse, yet seems to me, given the extract above, to signal something far more deeply felt, a longing to be appreciated and wanted, to relate to someone through helping perhaps. But as Will says above, he does not want to experience the disappointment again of being "ignored", it is too painful, so he resorts to the engineering discourses with which he is familiar, and which importantly, he identifies with the lost good object in his life, his father.

D.4.7. Discourses of the Self

The final theme contains psychological discourses that are self-oriented. These discourses reflect the donor's potential gains from altruism. They were not used by all participants, although for those who did draw on them, helping others and helping the self appear to be inextricably bound up with each other.

Extract 29

JC: Is that an important thing for you, that idea of it being as you say, significant, not that you've gone through your life being a 'good guy', but just a really big thing, did it feel like a really big thing?

James: I think it probably did towards the end, yes, er, I hadn't realised at the beginning, certainly when I knew I couldn't do it, it was a, I knew that feeling was going to be taken away from me and I had already got used to that feeling of I'm gonna have done something, and at a party you'd be talking to people and you'd be thinking, uh, I've actually done something here, and they'd say, "where you from, what you doing?" and you just don't tell them that at all, because it's got nothing to do with them, that's not why I'm doing it, but there's somebody, a bloke in Oxford, or whatever who's now got his life back.

JC: So, is it that you would have, you say you wouldn't have needed to tell people at parties or whatever but it was a knowing that you'd done something special...

James: Yeah, yeah.

JC: ...that was a...?

James: I think I would have on purpose not told people because I would have liked it if I'd met somebody like that then years later I'd found it, "What he gave somebody a kidney! What for no reason? Ah, that's really cool", yeah, I think I'd like that, that's nice, yeah.

JC: It made you feel what, I'm interested in that feeling.

James: It's that f-, that feeling that you've done something significant so if you died tomorrow, 'he will be the guy that...', 'ah yes, but he was like that', 'oh yeah, he gave somebody a kidney', you know, that's, that'd be important, nice, not just you haven't been, you haven't been nasty to people in life, but you could, something positive.

JC: Like a legacy.

James: Yes, you know, other people start a business, or I've never had kids, something like that, you know, you've brought up children, fantastic. I'm not really interested in kids, not really that sort of person, this was something different, hmm. (Lines 184 – 220)

This construction of altruistic donation would have allowed James to think of and experience himself as having done something deeply meaningful with his life that only he, and presumably the recipient, would know about, and that he wanted to keep all for himself. His link to not having children suggests Erikson's psychosocial goal of generativity in which the psychologically healthy individual is able to turn their energy to helping others; an ethical position of personal sacrifice (Meissner, 2003). James describes his fantasy of being at a party, specifically *not* telling people, keeping his good feelings about himself all to himself, like a precious secret. His fantasy is that if he *died*, people would find out and only then realise that not only had he been a "nice guy", but that he had also done something extraordinarily selfless. Tragically for James, this prize that would have allowed him to feel good about himself for the rest of his life has been taken away from him.

By submitting to his sister's sanctions James has been unwillingly placed in the painful position of the powerless younger brother. This would probably not have been easy to integrate with his construction of himself as "the luckiest person around". Through the discursive opportunity of the interview, he may have wanted to redress the threats to his identity posed by this inconsistency but the effect is that he has once again placed himself in a position of vulnerability and exposed himself anew to these painful feelings, and once again has to make sense of them in relation with another person, me. James uses the interview to construct a new, acceptable version of himself in which the blame for his having pulled out of the

donation is placed firmly with his sister while he retains for himself the idea that he will be able to fulfill his wishes in the future.

Altruistic donation enables donors to do something that is unquestionably ethical, yet at the same time, and problematically for some of them, it seems that it imposes constraints on what they are permitted to feel about themselves. If James allows himself to feel *too* good about what he has done and tells people, he risks undermining its value by benefitting from it in a way that is inconsistent with social expectations of altruism. This suggests that discourses of self-interest may be difficult for participants to reconcile with donation being constructed as “altruistic” and therefore only about helping another person. Consequently, James constructs altruistic donation as something that ought not be seen to give the donor rewards yet at the same time he does not deny that he was looking forward to experiencing rewarding feelings. Now, through disavowing public adulation for what he was going to do, he creates for himself a position in which he has been wronged, eliciting sympathy.

Participants who choose to describe altruistic donation in terms of it being something that they will also benefit from, such as Peter’s self-esteem, or Liz’s feeling of satisfaction at having done something good and unselfish, are able to draw on a discourse of being inherently implicated in other people’s suffering and that any benefit to another person will also benefit themselves in an uncontested way. They situate a positive relationship to the self in the context of helping another person. The discourses the participants use to construct altruism can be argued therefore to play a central role in the way they experience and understand themselves.

In direct contrast with James’ discourse of personal significance seen in the extract above, in which he acknowledges the significant personal feeling of pride that he expected to receive from donating, Richard explicitly rejects the idea that being an altruistic donor makes him a good person, resisting a discourse of reparation:

Extract 30

JC: It hasn't, you haven't had a, an easy life.

Richard: Erm, [.] p-, I, I, I was going to say I haven't had a successful life but that depends how you measure it, erm, from a material point of view, well, I'm comfortable, I've got what I want but I've always managed to live ok within my means, erm, I, but as I said before, I'm not assertive or, er, and, er, so, from a economical or, or, erm, work point of view I haven't progressed to any great heights.

JC: Do you experience that as a lack?

Richard: Yes.

JC: Are you conscious of it?

Richard: Yes I, I am...I think I'm a, I'm maybe not the most charming or, or, you know, but I, I'm a caring s-, er guy, you know and a loving guy, so, I, I, I don't regard myself as a total failure but I, you know, well in some ways a bit of waste of space, erm, but erm, I don't know, your question was about?

JC: Doing this [the interview], but I just wanted to pick up on that, that's a very harsh assessment of yourself, a waste of space, particularly in the context that we're talking, I wonder whether then for you the idea possibly, and I don't know whether this is going beyond what you've ever considered, the idea of donating a kidney is in some way a r-, a way of repairing some of those feelings in yourself about not having achieved perhaps what you might have liked to have?

Richard: No, I, I, I don't think so, I mean, I [2] erm, I have value within my world, I'm, I'm of value to my sons and family and friends, erm, I regard the body as a vehicle, er, I, I don't believe in an afterlife, erm, I er, d-, er, there's an extra kidney, it may as well be used you know, I don't think it's going to get me any kudos in, in heaven, or, or, or anywhere else, you

know, erm, er, I, hope that whoever gets it, it makes a difference to that person's life but I don't expect to ever get to have contact or recognition from that person and that's not the point of doing it, you know, it's, it's there, it may as well, if it's no loss to me and it's a gain to somebody else, why not? No, I, think that the vast majority of people don't have a significant impact on the world, erm, it's impressive to see those people who do have, and be nice to be in that position, it's just erm, an honest recognition, I'm one of the many, you know, not one of the few, if you like, er, that's all.

(Lines 742 – 781)

This exchange with Richard is immensely poignant; the extent to which he is prepared to make himself open and vulnerable in response to the questions is striking. From the start, he refuses my assessment of his life having been difficult, suggesting instead that he has not been successful, taking responsibility. Richard's description of himself as "a bit of a waste of space" and "one of the many" seems to signal his resistance to valuing himself. He refuses to claim credit for, or allow himself to feel proud of what he is doing, insisting again that altruistic donation is a purely rational response to the needs of another individual.

In stark comparison, Liz readily and happily links her altruism to a positive sense of self-worth. The way that she describes the pleasure that she gains from the idea of being able to help a person in need suggests a sense of accomplishment and importantly, agency. She is able, in this instance to really help somebody.

Extract 31

JC: Mm. From the way you talk about it, I get the feeling and the way you just used that phrase "my time" I get the feeling that this is something that actually is of great pleasure to you...

Liz: yeah it is, yes it is

JC: ...as an idea.

Liz: Yes it is, and you know it sounds terribly goody-goody but god you know, it, it, if it works, it will make such a difference to someone who's really struggling, and I just, that, that actually helps the probability an

awful lot, erm, but yeah, it does give me great pleasure, yeah. (Lines 102 – 110)

Liz makes a direct link between pleasure and the ability to help somebody. There is no dilemma here for her; she is able to reconcile helping another person with the benefits that she will accrue from her actions.

Extract 32

JC: Can you tell me a little bit more about the feelings that are associated with that pleasure?

Liz: Erm, I, [exhales] I suppose it's er, it's, it's quite deeply ingrained isn't it, the thing that you should try and help other people to erm, have a better quality of life if you can, and you know, so much of what we do, is to do with putting our hands in our pockets and donating to charity and stuff like that, and, and, that's fine, up to a certain point, erm, but I guess when you're a mother, you, there's always something at the back of your mind too that thinks if it was my child who was really ill and who was going to the hospital four or five times a week for dialysis and had no life at all, you'd be desperate for someone to donate, you know and obviously, you know I am an organ donor after I'm dead, and, and I will cont-, I'll do that any way, whatever's left! [laughs] er, if it's suitable, but erm, it just feels like something that can be done earlier in life with a better chance of working and, hopefully all round it's a better outcome at the end of the day. (Lines 111 – 129)

Liz's discourses here conflict with psychoanalytic theory that suggests that altruism is a defence mechanism against libidinal drives (A. Freud, 1936). By being open to the benefits of donation that are available to her as well as the recipient, Liz avoids being locked into potentially oppressive other-oriented sacrificial discourses. Helping others is linked by Liz to a feeling of personal achievement and importantly, personal involvement and empathy, she imagines herself in the place of a parent of a child with kidney disease and the "desperate" feelings that would result. Discourses of helping and self-gain are not in her case contradictory, but complement each other. In Liz's case, it is the welfare of the recipient that is privileged and Liz's personal benefit is secondary, yet nonetheless real and important for this.

Peter also considers the possibility that his motivation for donating is driven primarily by his relationship to himself, constructing donation as a means of shoring up self-esteem through doing something that will cause him to feel valued. He has a different reason for using discourses of self-gain. In an email he wrote after the interview, he said that the word that best described how he felt about what he was doing was “atonement”. Atonement is a powerful idea, often central to religious doctrine, that means reparation through paying a price for having done wrong. An atonement discourse therefore constructs altruistic donation as a price to be paid. Peter seems to be suggesting that he wants to help another person because through doing so he is able to help himself. In comparison with Liz, Peter constructs altruistic donation primarily as a self-help activity with an added benefit for the recipient.

Extract 33

Peter: But why would anybody want to be an altruistic donor? I don't know, it seems crazy, you know, but it's taken on its own life. I'm not compelled to do it, I have asked myself the question, I can't actually get a clear answer as to what am I getting out of it, because nobody does anything for nothing. I don't need to do it, I haven't advertised it any way because sometimes that might be a, oh you know, it might be reflected on you in a positive way, almost showing off, look you know I've given a kidney away for no reason at all. I don't think it's because of that so I then ask myself well 'why?' and I honestly can't put my finger on it, but I think that, you know, digging deep it might be something to do with being valued. (Lines 32 – 43)

In this discourse of valuing the self, it appears as though Peter is not thinking about the recipient to any great extent. This remains the case even as he constructs his decision to keep his plan to donate secret because that would look like “showing off” which is inconsistent with a discourse of altruism. This would seem to support the argument that an important function of donating is to increase his regard for himself, and the fact that another person will benefit provides him with a convenient and worthwhile way of doing it. When asked to expand on the idea that he didn't have any “thoughts” about the recipient, his answer is unequivocal, describing the benefit to the recipient as a “consequence” but “not the reason”:

Extract 34

JC: You don't have any sort of thoughts about...?

Peter: ...You take that for granted, you know, yeah, clearly it will help somebody, so when you sort of reflect on this yourself you're thinking, well you're not doing it necessarily to improve somebody's life, that's a consequence of what you're doing but that's not the reason, I think. So then you think well why are you doing it? So you feel good in yourself of having done something like this, which is probably why I'm doing it. So then you think, okay if that's why you're doing it, why do you need to do that? What is lacking in your life that you need such a big thing to happen in order for you to feel good about yourself? I think that's probably something in there that...it's probably something in there about being valued.

(Lines 129 – 139)

Switching again from the first to the third person, moving in and out of a subjective and objective position, Peter describes how something that has happened in his life has forced him to change his view of himself, and the psychological discourse of self-esteem that he uses constructs altruistic donation as a method for fixing the damage he has inflicted on himself, so that he can “feel good” in himself, an emotion that is currently “lacking”. Later on he remarks that the interview feels like ‘therapy’, suggesting that he is positioning himself as client, paralleling the way that he is using altruistic donation as a therapeutic opportunity.

Extract 35

JC: Do you feel that it [the fact that “life has gone downhill”] is because of something that you did?

Peter: Well yeah...But I suppose there is something internal in me that, you know, I, not consciously, but I built myself up and then I've taken it all away by doing something like this, so I'm kind of starting from the bottom again, not in terms of what other people think of me or you know how they value me, but probably in myself. You know inside you what sort of person you are, it may not be a true reflection of who you are but you know when you do something wrong and what sort of person you are. I still believe that I'm not sort of a bad guy, but I've made a mistake and I let it carry on and whether this kind of altruistic donation is some sort of

internal compensation to get over that, you know, I'm building up my, because I've thought about my self-esteem and I'm not conscious that I think it's low but maybe subconsciously that might be what's happening to...

JC: Something is making you think that might be some, there might be something in that?

Peter: Yeah and so...

JC: And you're linking that to having had the affair and this idea, this phrase "letting yourself down" is, do you feel as though you let yourself down, is that right?

Peter: It's probably something to do with that and therefore to build yourself up again or make yourself worthy in your own erm mind is probably something related to why I'm doing this, I suspect.

(Lines 446 – 488)

D.4.8. Emotional Investment in discourses: Peter

Of all the participants in the study, Peter's constructions of altruistic donation were the most fluid during the interview and his conversation took several contradictory turns as he wondered aloud about his motivation for donating. He was also most open to the possibility that for him, kidney donation symbolized something other than 'pure' altruism and this willingness to think symbolically, even psychoanalytically, may account for his openness to alternative constructions that seemed to both of us to be at times contradictory: "*I can't actually get a clear answer as to what am I getting out of it*". Parker (2005) argues that psychoanalytic discourse has become an accepted way for people to talk about psychology so that it in effect becomes "true" for them. One of the goals of critical psychology research is therefore to remain reflexive about this possibility, and Peter's engagement with unconscious material may have been in part a response to what he perceived was being asked of him in the interview (Parker, 2005). The idea that he must be getting something out of altruistic donation perhaps reflects his understanding of what he was being asked.

Peter began telling me about his decision to donate the moment he walked into the interview room, before I switched on my recorder. At the time I interpreted to myself that his need to talk about what he was doing was very great. A divorced man in his forties from an ethnic minority background, he had a successful professional life but a less happy personal one. He told me how a long-running affair had led to the end of his marriage. He had two teenage children whom he felt were unappreciative of him. It seemed that through the affair he had sought to recreate his experience of being a doted-upon youngest child, saying that through the affair, he was able to get the love and value he was missing in his marriage. He says that it was about "knowing what it felt like for the first time to be really valued very emotionally, intimately." (Lines 192 – 194)

There are two distinct and quite contradictory themes in Peter's talk, one self- and one other-related. In extract 33, in response to my first, open question, which does not mention motivation at all, he "thinks" that it might be linked to a feeling of needing to be valued, and that this is something buried inside him that he is "digging deep" to get at. He says "I honestly can't put my finger on it" but in his next answer he changes his mind, appearing temporarily to reject the idea that

there is any personal emotional significance to donation and that it's about pragmatically "offering to help someone" and that it is not "a big deal".

JC: I'm really interested in this idea that you can't, you, you, yourself don't even know in a sort of reasoned way why you're doing it and I was wondering about whether it, whether thinking about the feelings that go with it may kind of shed some light on it. I just, can you, thinking back to that time when you had that initial reaction, that "Oh that's sort of interesting" reaction, what were the feelings, can you remember?

Peter: I don't think there were any sort of deep emotional feelings about erm some sort of great gesture or, or, or even a sort of evangelical type of erm, no, that's the wrong the word, it's er, some sort of sacrificial erm thought process, erm. It was very, very matter of fact; it's like erm offering to help somebody who, who you think might benefit. I know that that's my general attitude anyway, erm to the embarrassment of my children, erm and this was perhaps an extreme form of that erm, and I don't think, you know, I don't think it's a, I still don't think it's a big thing although other people I know would think, well hang on this is a reasonably serious operation which you don't need to do and if you thought about it, you know, you weigh up the pros and cons, erm, it's somebody's life that, like a relative's life, doesn't depend on it so [...] you know why are you doing it? Erm it's like a snowball, it has taken on a certain momentum which, not, not against my wishes, it's not as though I can't stop it erm emotionally or otherwise, I'm not committed, I'm not frightened of erm chickening out. It, it doesn't, that wouldn't bother me erm, but it erm [...] it wasn't a sort of sudden thing, it wasn't a heavily emotional erm, my perception is that it's not, that there isn't erm, er an emotional reason behind it I just, I just suspect that it's to do with me in a very simplistic way being helpful.

JC: But you don't feel it's a big thing?

Peter: In terms of a personal erm sacrifice, or that I'm exposing myself to unnecessary risk, I don't perceive it as that. It may be that, but it's not, I don't think of it as a, as a big deal. (Lines 52 – 82)

Having constructed donation in terms of being valued, Peter now denies that there is an “emotional” reason to donate, seeming to contradict himself. At this point, I would like to analyse my own emotional investment in the discourse, and ask myself the question I was asking Peter. Why was I interested in altruistic kidney donation and what was my initial response on learning of its existence? My response to it reflects my own unconscious process and from an inter-subjective framework, in which meaning is co-created, this can be used to gain a more nuanced understanding of Peter’s experience. When I reflect on my own response to the idea of living organ donation, the first thing I notice is also conflict; a distinct yet unfocused sense of uneasiness, even queasiness around the intimacy and the violation of bodily integrity that it involves. I feel that there is a sacrificial element to it, the donor is submitting to something and not trying to resist any longer, as though they are offering themselves up. Peter describes the process as “like a snowball”, suggesting that he is allowing himself to be taken along by it. This might be interpreted as a way for him to avoid having to think anymore about the feelings that go with it, feelings that might be either unavailable to conscious evaluation because they need to be defended against, guilt or shame for instance. There does seem to be evidence in the text to support the suggestion that Peter is reluctant to experience the unpleasant feelings that go with his attempt to increase his sense of self-value, for instance, when he denies that his decision to donate is not “heavily emotional”.

In extract 35, Peter returns to the theme of valuing himself and constructs altruistic donation as a form of internal compensation for a wrong he feels that he has committed, a form of reparation (although it is not clear to whom, to himself possibly?) through the mutual act of helping:

“I still believe that I’m not sort of a bad guy, but I’ve made a mistake and I let it carry on [the affair] and whether this kind of altruistic donation is some sort of internal compensation to get over that, you know...”

Peter’s discursive about-turns left me feeling disoriented during the interview. Is altruistic donation an emotionally significant act for him or isn’t it? I am left with two conflicting interpretations of Peter’s split emotional investment in the discourses he draws on to describe altruistic donation, with no way of choosing one over the other. In Peter’s active, questioning stance to the research interview I have wondered whether there may paradoxically be the possibility that he does

not actually want to think too deeply or feel too strongly about becoming an altruistic donor because of the very uncomfortable feelings associated with his sense of the loss of self-worth. Perhaps he is using the interview to let himself *feel* as though he is actively considering his motivation, except that it's actual function is a sort of emotional smokescreen. From this perspective, his discursive repertoires might be seen as having a defensive function. Each time that he drops his guard and describes donating in terms of self-value, he appears to then reverse his position, downplaying the emotional significance of altruistic donation.

After the interview Peter sent the following in an email:

"There is only one thing that I was thinking about subsequent to the interview and it was that the word I was searching for during our talk; "atonement", which seemed to encapsulate probably what was and is going through my mind as to why I might be doing this, together with all the other reasons I gave you".

The notion of 'atonement' does seem to lend evidence to the argument that Peter's emotional investment in his particular construction of altruistic donation affords him a way to subjectively experience himself as acceptable again, to feel loveable once more. He was treating the research interview like a confession. Does this mean that donating his kidney means that he will feel absolved of his guilt? It seems that Peter is donating not to save the recipient of the kidney, but to save himself. By giving a kidney to a stranger, he says that he is doing it simply to help the individual, but in unconscious fantasy, we might think of the way in which he is representing and attempting to repair the damage he has caused in others and in himself. He says, with a sense of careful consideration, that the value he will gain from donating is not about getting something [such as praise or admiration] from other people, but; *"the value is within myself"* (line 219).

I have suggested, based on the text, the research relationship and inter-subjective experience, that one possible psychoanalytically informed explanation for what is happening might be that the feelings that underlie Peter's desire for "atonement" are too anxiety provoking to be easily bearable for him. Through the possibility of altruistic donation, Peter might have found a way of ridding himself of these uncomfortable feelings and re-experiencing himself as the kind, caring, generous person that he feels himself to have become distanced from.

D.5. Conclusion

The aim of this research was to analyse discursive constructions of altruistic kidney donation in interviews with prospective donors, and to explore the subjective experience these discourses allow donors and others. The intention was to develop a more useful understanding of how these individuals think about their wish to donate. Currently, people who want to donate a kidney to a stranger are either lauded, as in the media, or regarded with implicit suspicion and as a potential risk, as in the academic literature. This binary understanding of altruistic donors constructs them either as heroes or as potentially 'mad', and forecloses on the possibility of a more nuanced, and therefore useful, conversation, one that is able to take account of donors' own discourses and the implications of these for the practice of altruistic kidney donation.

The methodology of the study has integrated several analytic frameworks; a Foucauldian approach to discourse analysis, positioning theory (Davies & Harré, 1990), the psycho-discursive approach of Wetherell (1998) and psychoanalytic theory (Frosh & Saville Young, 2008). A non-pathologising psychodynamic approach to counselling psychology has been drawn on to bridge the epistemological gap between social constructionism and the psychoanalytic assumption of an unconscious mind that can be interpreted.

5.1. Summary of analysis

A focus on 'discourse-as-knowledge' (Hook, 2001, p542) has driven the discourse analytic approach. The idea that psychological health and altruism are incompatible came originally from psychoanalytic theory with the work of Anna Freud (1936/1966), in which altruism was constructed as pathology. It is still characterized by some psychoanalytic writers as an adaptive defence linked to narcissism, even though it may not be considered pathological (Seelig & Rosof, 2001). This pessimistic construction of altruism in psychology was compounded by a "hedonistic paradox", the theory of self-interest posited by behaviourist and biological psychology in the middle of the twentieth century that positioned altruism as incompatible with dominant theories of human behaviour. Altruism has therefore been constructed for many decades as an interesting intellectual problem that belongs more to the theoretical discipline of philosophy than psychology. In recent years however, a more optimistic evidence base has been

proposed by social psychology in support of a claim that altruistic motivation and behaviour is founded on empathic understanding (Batson, 2011; Mikulincer et al., 2005). This allows for the possibility of altruism in psychology, re-constructing it as a positive human characteristic with a biological base, rather than as evidence of psychopathology. What is more, this approach recognizes the possibility that an individual's motivations to behave in an altruistic way may not be available to conscious thought (Batson, 2011).

For coherence in presenting the results, participants' discourses were grouped into three broad themes. The first group includes discourses in which altruistic donation was constructed as *other-oriented*, drawing on notions of altruism, morality, sacrifice and ethics and as being for the sole benefit of another person, not the donor. These discourses were consistent with religious and socio-cultural traditions of helping those in need. The needs of the self were almost aggressively minimized through these discourses, but paradoxically, they also operated to construct the donor as omnipotent life-giver, directly intervening to prevent the death of a stranger. Anonymity meant that recipients were positioned as virtually invisible; silent, disempowered and dependent on the donor. Some participants resisted having to think about the recipients and their experience, other than in abstract terms. Emotion discourses were drawn on to describe the feeling of being compelled to donate and of it being something felt to be "obvious" to the donor, as something defining about their identity.

I have argued that these discourses of obligation make donors' claims difficult to contest. The assertion of obviousness enabled participants to resist questioning in the interviews to some extent, preventing a conversation about whether what they were proposing to do was in need of examination. Emotion discourses created an important drawback for participants however, since they entailed a risk that others; in particular family and friends, would think that the donor was 'mad' for what they were doing. In these disagreements, emotion becomes discursively equivalent with irrationality. The experience of a negative reaction from family and friends was common to all the participants. Participants struggled against being positioned in this way by others, using rational discourses to accomplish this. They retaliated by turning the tables on their detractors, labeling them the 'selfish' ones.

The decision to donate apparently tended to evoke a degree of anxiety and opposition in other people, to the surprise of the participants, who had not anticipated such a reaction, in part this was because they saw it as such an “obvious” thing to do. To counter this response, participants turned to “rational” discourses of medicine and engineering, which incorporated ideas about acceptable levels of risk and the commodification of body parts, allowing them the subjective experience of being both right and moral. Furthermore, keeping the decision as private as possible was not only consistent with available discourses of altruism, but had the added benefit of protecting donors from the threat of further perceived attack. Rational discourses were used to construct altruistic donation as a safe, measurable, quite unremarkable procedure. Through them, participants positioned themselves as sane, highly rational individuals, aligned with the culture of science and medicine. Doctors and other medical professionals are usefully positioned by these discourses as trustworthy and benevolent, with only the donor’s best interests at heart.

Parallels were drawn constructing altruistic donation as equivalent to other types of medical donation, such as blood and even organs after death, as though there were no difference. Even the donor’s death can be constructed as being acceptable using these discourses. This is a somewhat paradoxical idea in the context and runs directly counter to prevailing medical discourses in which it is unacceptable for the donor to be harmed. I have suggested that this dualism, separation of the mind and body, in which the self is not associated with the physical parts (which can die) might be a way of managing feelings about death. By reducing their physical bodies to parts that can be re-used, participants might to some extent find a way to face their own future non-existence. In this way, risk discourses enable them to disassociate themselves from their own mortality, reconstructing their corporeality in terms of utility.

Discourses in the third group were self-oriented, and included self-esteem, self-worth and reparation. Some donors resisted these discourses and the attendant construction of their own needs outright. Those who did use them constructed altruistic donation as a legacy; describing it as a way of giving something back to the universe in return for their own perceived good fortune. One participant drew on an atonement discourse to suggest that for him, donation was a process of reparation for damage he had inflicted on his own psyche through past behaviour. These discourses were often highly personalised – the good feelings that would

be created by donating were private, to be kept safely inside, like a source of nourishment for the future. By keeping any personal benefits protected inside and hidden away, deflecting attention and praise, discourses of self-interest could be reconciled with those of altruism as being solely for the benefit of another person. For the one participant who was able to reconcile herself to the idea of benefitting from donating in a positive way, it seems that she was able to do this by embracing the communal nature of suffering, able to think about the recipient as an object and feeling herself to be implicated in others' lives, thus avoiding the notion of altruism as self-sacrificial.

The methodological approach of this study integrated a social constructionist discourse analysis with an additional, intra-psychic and inter-subjective framework. The extracts for this next level of analysis were chosen because they represented moments in the interview in which the participant seemed to have a particular emotional investment in the discourses they were using. Overall, the use of a psychoanalytic framework provided a way of engaging with the possibility of inter-subjective meaning-making in the interview and for a tentative formulation of the participants' unconscious investment in the discourses they chose to use. Although the discourse analysis allowed for some consideration of the possible subjective experience granted to the participants by their discursive constructions, employing a psychoanalytic framework allowed this understanding of subjectivity to be made richer, or "thickened" as Frosh & Saville Young (2008) suggest. However, the extent to which a psychoanalytic formulation could be made was necessarily limited by the amount of personal information that could be gathered in the research interview and the fact that interpretations could not be given to the participants for validation.

In these accounts of participants' emotional investment in their discourses, psychoanalytic ideas about the way individuals experience themselves and other people through a mixture of fantasy and reality; object relations and defences against anxiety were used to theorise possible unconscious motives for donating. From this perspective, it is possible to suggest that for some donors, altruistic donation may have relatively little to do with their feelings and thoughts about the future recipient of the kidney, and may be formulated instead in terms of the donor's unconscious experience of self and other in fantasy. Altruistic donation can be thought of in terms of a possible response to loss in the donor's life, a way of making concrete feelings about loss that cannot be symbolized in language.

This suggests a profound rethinking of the notion of “altruistic”. Donation therefore becomes an embodied and psychic response to perception of a socially and technologically constructed need. In allowing the violation of their physical integrity, the breaching of their actual physical boundary, a physical space is created inside the donor, and something of their unconscious experience may be communicated, as though they are saying; “Look at what I have given of myself”. Within this actual space created in their torso, an unconscious recognition of an intra-psychic or inter-subjective lack may be represented. Frosh’s (1999) description of Lacan’s theory is useful in thinking about how this lack symbolizes the donor’s unconscious fantasy of their relationship to the recipient; “Lacan focuses on how the subject becomes formed in ‘otherness’, how identity is always produced by the insertion of the subject into something outside itself” (p139). It is interesting that participants do not seem to allow themselves to experience any anxiety at the invasive nature of the operation and this may say something about the extent or not to which they experience themselves as bounded. Instead, anxiety is split off for other people to feel and is represented in the tension that is created between the discourses outlined above. Concerns about altruistic donation are felt not just by the families and friends of donors, but also by the health professionals who engage with altruistic donors. These concerns seem never to be acknowledged in public however, as if to do so is somehow unacceptable. In the media any discussion of altruistic donation is constructed only in terms of its morality, which is found to be unquestionably good and the donor is fervently idealized. We might ask ourselves what would a more complex discourse look like here?

5.2. Relating to existing knowledge

Comparing the current study to existing research in the same area is difficult because there are no qualitative approaches to altruistic organ donation that have been found at the time of writing. The closest study in methodological aims is Franklin & Crombie’s (2003) study of directed kidney donors. Franklin & Crombie (2003) present a phenomenological content analysis and ethnographic study of together, but do not attempt to integrate them, treating them as two separate but compatible approaches.

Existing research on altruistic donors is interested in their psychological assessment, mostly before, and occasionally after, donating. I have argued that

participants' and expert discourses around altruistic donation are likely to have been influenced by the implicit association that this literature makes between altruistic donation and the possibility of psychopathology, requiring donors to defend themselves against the presumption of the possibility of mental illness. The current study therefore represents an addition to the existing research, in that its methodology is guided by a non-pathologising stance in which understanding the subjective experience of six altruistic donors is the goal. In this section, I will draw out the points at which the findings of the current study can be related to what is already known about altruistic kidney donation.

As reviewed in the first chapter, most of the academic literature on altruistic kidney donation to date has focused on efforts by transplant assessment teams to rule out the possibility of mental illness or personality disorder in the donor. This association between altruistic donation and potential mental illness is not reflected in the media however, which feature only stories of heroism and self-sacrifice. But it seems that these discourses of selflessness are ignored or rejected by those who are closest to the donors, their siblings, parents and friends, who instead draw on discourses of madness to criticize the donor's intentions. They are the sole negative voices that have to be confronted by the donors, and this often leads to resentment and confusion. This finding has been reflected in one of the very few outcome studies of "altruistic" donations (Massey et al., 2010). The risk-averse discourses of the experts, and the way in which these coincided with what seemed to be the positions taken by the donors' family critics, resulted in the same discursive effect; the positioning of the donor as "possibly mad".

Expert discourses of psychopathology can be accounted for in terms of the legal, ethical and social responsibility of the medical authorities to protect the donor (and by extension, the hospital trusts) from potential harm, and although this aim is not disputed, I would like to suggest a further explanation for it using the experience of the donors' families. Within the current study's chosen methodology, the source of the families' opposition cannot be understood from donor discourses alone, since a psychoanalytic and psycho-discursive psychology perspective would suggest that they likely contain an element of fantasy and projection. I have suggested that one possible explanation for the anxiety felt by others is that it represents an otherwise unspoken social response to the idea of organ donation.

The idea of social defences against anxiety in the medical profession was first suggested by Isabel Menzies Lyth, in her study of the unconscious institutional processes at work in nursing (1960). Lyth (1960) drew on a Kleinian formulation in which powerful symbolic representations of unconscious infantile anxieties require a defensive response if they are not to become overwhelming. These defences are then built into the socially structured systems of medicine and the hospital (Lyth, 1960). I would like to extend this argument to organ donation and suggest that unconscious anxiety may also underlie policy and the response of professionals to altruistic donors, which is itself a reflection of the focus in the expert literature on assessment and potential pathology in the altruistic donor. Professionals involved with donors are able to defend themselves against anxiety through the application of these discourses. Medical discourses of the desperate shortage of organs for transplant are used to further shore up this group defence.

Within medical discourses, where death is constructed as a technological failure (Lock, 2002b), a parallel process with that of the altruistic donors in this study can be argued to be taking place, in which death is consistently disavowed. A British Medical Association report into organ donation argues that; “people are still dying unnecessarily” (BMA, 2012, p5). There are two interesting ideas contained in this discourse; firstly, the increase in the number of people awaiting donor organs is presented as a natural event, rather than as a product of the technology of transplant surgery, and secondly, it contains the idea that death is unnecessary.

Such discourses allow for the suggestion to be made that patients who are about to die who have consented to become organ donors, are at their last moment, artificially ventilated in order that their organs be kept alive for transplantation in a procedure called “elective ventilation” (BMA, 2012). Whilst the BMA does not currently advocate this procedure, arguing that it is interested only in opening up debate, the fact that it is part of an apparently rational debate on organ donation, with no corresponding discussion about its implications for the nature of the death of the donor suggests that the medical profession is itself engaging in defending itself from thinking about death. Medical discourses on organ donation currently do not seem to allow a space to question what might be going on here. Without explicitly recognizing the inherent paradoxes, the same report points out that advances in the medical treatment of trauma have led to a reduction in the number of deceased organ donors.

Anthropologists have characterised the shortage of organs as itself a social creation, arising as a result of technology and the development of transplant surgery and immuno-suppressant drugs (Lock 2002b; Scheper-Hughes, 2007). A new charity in the UK, started by altruistic donors, recently began urging people to “Give a Kidney”. From the psychosocial perspective employed in the current study, it can be argued that the medical and psychology literature is currently failing to address important ethical questions about the extent to which individuals feel compelled by these official discourses of shortage and feel that they have to respond, and to think about where this process might logically lead, as well as the ethics of allowing one individual to give away a part of themselves to another. Scheper-Hughes (2007) argues that living donors should not be honoured because of the sense of obligation that this creates for some.

Discourses of trust in medicine and medical people were noted in Fellner & Marshall’s (1968) study of directed kidney donors, and are also present in the discourses of the participants in the current study. This highlights the altruistic donor’s deliberate decision to engage with the clinic. With this particular method of helping, altruistic donors are choosing to put themselves into the hands of doctors and nurses and engage with a setting in which they can be cared for and examined thoroughly in many hospital visits and tests. There may be a further parallel here with the work that medical professionals (and psychologists) choose to do. Speck (1994) suggests that for people who choose to work in settings where people suffer, or are ill and dying, an unconscious attraction to this kind of work lies in the way that the work serves to maintain a fantasy that bad things happen to other people.

The compelling nature of organ donation for the participants in the current study has also been found in existing research with directed donors (Franklin & Crombie, 2003; Gill & Lowes, 2008; Lennerling et al., 2003). In these studies, the reliance on emotions in the decision, as opposed to “rational” thought, has been identified, but not questioned. The current research goes further in addressing the way that altruistic donors use ideas about emotions and rationality in their discursive repertoires, suggesting the possible subjective experience that each allows for. The current study has also used psychoanalytic theory to understand the feeling of instant recognition on the part of participants to the idea of donating and discourses of “obviousness” with which they describe these feelings. This dual focus has shown how altruistic donors use emotion discourses to

demonstrate their goodness, and rational discourses to resist being positioned as emotional if they perceive this to be a criticism. Their instantaneous response to the idea of donating is constructed as evidence of the “rightness” of what they want to do.

I have found Lemma’s (2010) work on body modification to be useful here, in which she describes how people feel “compelled” to modify the exterior of their bodies, either in actuality or in fantasy, and argues that this feeling of compulsion signals that the body is being used to communicate something of the individual’s internal world and object relations. This has resonance for the current study, in which this feeling of compulsion was common to participants. Indeed, a common theme in donors’ discourses is their “feeling” or “knowing” that this was something they really wanted to do, or had to do, once they knew that it was possible. Lemma writes; “Our relationship to our body is probably the most concrete marker we have of how we feel about ourselves and about others” (2010, p7), and goes on to describe how because the body develops *in relationship* with others, in changing the body, something is being expressed about the “quality of internalised relationships” (p4). I suggest that this notion of the embodied nature of relationality can be applied to the altruistic donors in the current study. Organ donation is an internal modification that might be thought of as creating a space to allow the donor to start object relations, reflecting Lacan’s idea of subject formation (Frosh, 1999).

5.3. *Reflexivity*

Reflexive work has provided a way of thinking about the epistemological approach of this study. Specifically, reflexivity has focused on what can legitimately be interpreted in research. In this section, I show how important it has been to attend to my own responses to the discursive practices around altruistic donation.

While thinking about possible psychoanalytic interpretations of participants’ discourses, I experienced a feeling of doubt in response to talk about the ‘obviousness’ of what they were doing. I wondered whether this signaled a resistance to thinking about possibly difficult feelings around donation, a way of foreclosing on ambivalence. Altruistic kidney donation can be very clearly constructed as an ‘obvious’ thing to do in medical and utilitarian terms, with its low risk of physical harm and clear benefit to the recipient. And yet, it is striking that in

spite of the rationality of these discourses, a sense of unease and anxiety remained for me when I reflected on the feelings these discourses evoked. Significantly I think, the ambivalence I have felt from the start of the research has not been changed by the process of thinking very carefully about what is being said and possibly felt by donors. I have understood this as a reflection of my unconscious relationship to the positions made available – the “interplay of subjectivities” that arises in the interview that Rizq (2006, p622) describes, and I attempted to make use of it in the psychoanalytic interpretive strategy. This illustrates a strength of the method, in that it allows for reflexive work on the part of the researcher to be fully incorporated into the analysis, rather than remaining as an afterthought to be accounted for like a confounding variable in quantitative research.

Throughout the entire period throughout which the research has been conducted, I have found myself shifting constantly between two positions in relation to altruistic donation; I am split in my response to the notion of organ donation. At times, I find that I can (almost) take the position of the donors themselves and accept their constructions of donation as a purely humanitarian thing to do. I admire their generous offer in response to a need in others. At other times, I experience an indistinct uneasiness and anxiety that is difficult to describe. This uneasiness seems to be in response to the idea of the body as a machine, a source of organs that can be divided up and stuck into other body machines. I believe that anxiety about this “hybridization” (Lock, 2002) is a common response and is reflected in periods of public anxiety that arise from time to time in response to advances in medical and scientific technology that are perceived to be “unnatural”.

It is interesting to consider where this ambivalence or split-ness comes from, and this is an area in which psychoanalytic theory has been useful in the current study. I would like to suggest that what I (and apparently others) experience in response to donors, in addition to “boundary anxiety” (Howson, 2004), may also be partly envy and discomfort at being made to feel less ‘good’. The ‘sacrifice’ that altruistic donors make positions those of us who do not want to give away one of our kidneys as not as good, as more selfish, as less willing to care for others. Asking the question, which donors implicitly ask through their action; ‘Why isn’t everyone doing this, why aren’t I doing this?’ leads to the possible conclusion, that I must not care about other people as much as the participants do and am therefore

more selfish. Reflecting on this is uncomfortable. I would rather not have this feeling. It is much easier to turn the approbation on the donors and I argue that this is one of the reasons that the people closest to the donors are the most critical of them.

Through a reflexive attempt to dissect out which responses are personal, internal and relating to my own subjective experience, and which can be considered to be objective and therefore “fair” and valid (if any), it is possible to understand how difficult a task it is for society and the clinic to respond to altruistic donation. My own misgivings highlight the extent of the ethical responsibility faced by the medical and allied professionals who are being asked by prospective altruistic donors to facilitate their wish. The confusing array of emotions and beliefs that constitute any considered response to altruistic donors has to be somehow organized into a coherent approach in which the needs of many have to be considered. This places an enormous responsibility on the individuals who are tasked with taking the decision as to who will, and who will not, be allowed to donate. Through the use of a method that looks at both the social and the psychological, the current study is able to acknowledge the tensions, complexity and contradictions that are inevitably felt by these individuals, and points to a possible site of intervention for Counselling Psychology research of this type.

5.4. Evaluating this research

This section contains a discussion of the methodology used in the current study. Considerations of validity in qualitative research have been discussed in the methodology chapter. The discourse analytic and psychosocial methodology used in this study evolved out of a process of thinking about and trying to understand altruistic kidney donation. This approach begins with Foucault’s theory, which suggests that as individuals we are constituted by discourses that are available to us in the social realm. The attention to the social construction of our embodied selves is supported by Lemma (2010), who suggests, “the body...is a social body” (p19) and Lock (2002b), who extends the idea by arguing that organs themselves also have social meanings. Participants in the current study construct their physical selves in ways that are in line with contemporary medical discourses of the body. This view of the body draws on mechanical discourses and the assumption that we all possess potential “spare parts” that can be used to save

the life of another individual once they can no longer support life in their original body. In expert (medical) discourses of organ donation (eg. BMA, 2012), saving lives becomes the paramount and utterly uncontested goal. Public discussion expressing any doubts towards this approach to living and dying is resisted through the use of these expert discourses, seemingly because of the fear that any questioning of the ethical basis of transplant surgery will result in a negative effect on the numbers of people offering to donate their organs. Lock (2002a) argues that biomedical knowledge and practice reifies and fragments parts of the body.

“In order for body parts to be made freely available for exchange, they must first be conceptualized as thing-like, as non-self and as detachable from the body without causing irreparable loss or damage to the individual person or generations to follow” (p71).

These discourses assume that the idea of not wanting to donate organs after death is irrational, and may even be immoral, since morality is constructed in terms of the number of lives saved from disease and death. Participants in the current study also drew on discourses in which they described their motivation to donate in ways that are consistent with social constructions of altruism. These discourses are widespread in the culture and are particularly prevalent in the moral codes of the major religions. Additionally, all participants had already entered the formal and legal assessment process at hospital and had become practiced at using discourses of self-sacrifice when they are asked about their motivation to donate. The social aspects of altruistic donation are unavoidable and powerful. I would argue that attending to the social constructions that altruistic donors draw on provides a method capable of answering the first two research questions in the current study.

However, a pure social constructionist approach does not allow much scope for the possibility of linking linguistic constructions with internal experience (Willig, 2008) but by using in addition psycho-discursive and psychosocial methods, it becomes possible and indeed necessary to question an individual's possible subjective investment in their discursive positions and how these “can be seen to intertwine with the constructive power of discourses” (Frosh & Emerson, 2005,

p308). Judith Butler (1997) has argued for the need to integrate Foucault's theory of the way in which social power is taken in by individuals to constitute the personal and psychological with a theory of the psyche, and to use the two perspectives to help us understand the other. I would situate the current research in this approach. The psychoanalytic notion of the unconscious offers a way to think about a participant's emotional investments in the discourse they use. Lacan argues that the unconscious subject and language constitute each other; language is the medium by which we understand what it is to be human (Parker, 1997).

In field notes, I recorded the sense that I had during and immediately after several of the interviews that in focusing solely on discursive constructions, I would be missing the emotions that were underlying participants' discourses. I realized that I was certainly neglecting an important aspect of my own experience of responding to participants. The intensely physical nature of the relationships that altruistic kidney donation involves was too visceral – literally too *embodied* - to be satisfactorily accounted for with a purely discursive focus. For this reason, it was important to consider how participants related to their own embodiment, both consciously and unconsciously, as well as how the body is constructed socially, and what this might signify in psychological terms. In light of this, the absence of holistic body discourses in both expert and participant discourses was striking. It was as though the body as a subject was not relevant to a discussion about organ donation other than in terms of its utility. Only during periods of public disquiet, such as during the Alder Hey scandal, does the body and society's relationship towards it come temporarily into focus, only to be repressed with "modern" discourses of logic and rationality.

One early, striking result of attending to participants' emotional investment in the interviews was a sense that some were discursively avoiding making links between their behaviour and their feelings. This pointed towards the possible interpretation of altruistic donation as an unconscious communication. Participants' tendency to describe their decision in concrete terms was illustrated in the way that all of them drew on risk discourses, rejecting self-interest. Psychoanalytic theory might suggest that for some participants, self-interest has been split off or "given away" because it is on some level unacceptable. I have argued that understanding altruistic donation is best served through exploring both

the donor's use of social constructions – for organ donation is an acutely social behaviour, constructed, legislated and assessed according to the discourses available to a subject at a certain cultural and historical juncture – as well as by thinking tentatively about what may be taking place intra-psychically and inter-subjectively for the participant in this intensely personal, intimate response to the suffering of a stranger, or indeed, their own suffering.

Parker (2005) urges the researcher to think about the story told by the participant in the interview as *one version* and to ask why it takes the form that it does – it is only “a particular account on a particular occasion” (p67). Frosh & Emerson (2005) agree when they argue that interpretations of the text must be treated reflexively, as discursive constructions themselves, the effects of which can be examined and discussed. There is a danger of using psychoanalytic theory to contradict the participants and invalidate their discourses (Parker, 2005). However, I have found that the struggle to remain rigorous without feeling that I am being critical of the participants has in fact been helped through using psychoanalytic theory. It has given me a third position (Britton, 1988) and the creative space to think about what the possible unconscious experience of the donor and others, at an individual, institutional and societal level.

An evaluation of this research requires a critical appraisal of the extent to which I have been able to satisfactorily analyse and interpret using the two different analytic frameworks - the discursive and the psychosocial. The potential for contradiction that is inherent in an attempt to synthesise these two epistemologies comes to the fore in thinking about the ethical treatment of participants' research interviews, which I have discussed. There is a risk that the analysis of the extra-discursive can function as a way of undermining the participant's own discourses. That is, by making a psycho-dynamically informed interpretation of the participants' words and actions, I will be saying that I, rather than the participant, know what is really going on. This would be unethical from a social constructionist standpoint.

To address this inescapable tension between the two epistemological positions, a tension, which I would argue is also present in counselling practice that uses a psychodynamic framework, in my presentation of the analysis in the current study, I have chosen to separate the discursive analysis from the extra-discursive analysis. The reason for this was to make my methods as transparent as possible,

but one perhaps unwelcome effect of this separation has been to artificially highlight the differences between what the participant is saying, and my interpretation of their possible emotional investment in particular discursive resources. One way to assess whether or not the psychosocial analysis is experienced as an imposition of theory that has no meaning for participants would be to integrate these two analytic frameworks in the writing up of the analysis. If the two could be synthesized in a way that would read as internally coherent, and grounded in the text, I believe that this would go some way towards being able to argue that the two analytic frameworks can co-exist.

In place of this, I have tried to ensure that in writing the accounts of the participants' emotional investment in discourse, there is nothing in my interpretations that runs directly counter to, or appears to contradict what the participants are saying. Keeping in mind the two-person psychology of relational psychoanalytic thinking has helped in this, because it has required a reflexive and explicit focus on my own role in the co-construction of meaning. A psychoanalytic understanding of the importance of ambivalence in subjective experience may also be helpful here.

The analytic process has highlighted the risks that are inherent in any attempt to tease out the social and the discursive from the psychological and the internal, and this reflects my own position, in which the social and the psychological in our subjective experience are never truly isolated from each other. I have undoubtedly experienced the attempt to hold these two analytic frames as difficult, and in response to this, have endeavoured to phrase my interpretations as tentative suggestions, rather than statements. This is particularly important in a psychosocial analysis, but it also applies to a large extent to a discourse analysis. I think that this is where my experience as a practitioner has been useful, giving me the confidence to take this stance. This is important because making a suggestion, or asking a question, in which the researcher acknowledges that this is a subjective process, does not have the same ethical implications as making a statement as though it were fact. As a counselling psychology researcher, if I am to make any kind of interpretation whatsoever, I feel that it is important to give myself permission to ask questions, without needing necessarily to arrive at an answer. This after all, is also what we strive to do in our practice, for our clients.

5.5. Strengths and limitations of this research

In using the term “altruistic donation”, this research is inevitably positioned within contemporary social and cultural discourses and the associations with altruism these entail. This may have resulted in certain alternative discourses not being made available to me in the interviews, discourses that do not fit the cultural expectations surrounding altruism, for example, and this is a limitation of the present study.

Recruiting participants through the NHS meant that participants were protected as far as possible from potentially negative effects of taking part in the research, part of meeting the ethical requirements of a study of this nature. However, my inevitable association with the hospital department in which the participants were being assessed will likely have had the effect of suppressing possible discourses in participants’ interview. This will have a negative impact on validity (Yardley, 2008). To counteract this as much as possible, I separated myself from the hospital in the participant recruitment and interviewing process, but it is nevertheless likely that a link with the hospital would have remained in the minds of the participants. This may have had the effect of encouraging particularly clinical discourses and discouraging discourses that participants considered did not fit with an “official” viewpoint and may explain the preponderance of this type of logical discourse.

In a similar vein, my role as a trainee counselling psychologist would have inevitably created beliefs on the part of the participants about what I was expecting from them, and may have led to them using psychological and psychoanalytic discourses in their conversations with me. Parker (1997) describes how psychoanalytic discourses have become part of the way that people understand what psychology is, with the result that individuals describe themselves using psychoanalytic ideas. It has been necessary therefore to be alert to instances where participants have used psychoanalytic discourse and to take care not to collude in this practice and use these discourses as evidence of the “truth” of such theory because it comes from the participant. Parker (2005) is critical of “psychoanalytic” research because it is; “...an analysis of contradictory pathological experience as itself already interpreted by psychoanalysis” (p105).

A strength of this research is that it meets Yardley's (2008) criteria for validity in qualitative research, which are outlined in the methods chapter. Taking Frosh & Saville Young's (2008) measure of validity in psychosocial research, the current study's analytic approach to the text has generated useful material for thinking about the psychological phenomena that arise in relation to altruistic kidney donation. Only through the detailed consideration of the social expectations placed on the individual and encoded through discourses, together with the effect of, and response to these discourses by the individual from an internal, psychological perspective, is it possible to come to a holistic understanding of such a complex act. Attending to either the discursive or the phenomenological in the case of altruistic donation would have, in my opinion, limited these findings.

Another strength of this research is topicality. At the time of writing, the British Medical Association has just published a lengthy report aimed at generating public debate on increasing the numbers of organ donors in the UK (BMA, 2012). It is possible to argue that by examining the language used by altruistic kidney donors to explain what motivates them offers a perspective on the ways in which society and individuals think about organ donation that can contribute to this debate. More practical applications of the research will be considered below.

5.6. Suggestions for further research

I have found the absence of the recipients' voices in this research to be striking. They are neglected in the discourses of the donors in the current study. There is a presumption that recipients of organs will be grateful and willing recipients of altruistic donors' kidneys. This is in contrast with evidence that patients who receive transplantations from deceased or related donors experience ambivalent reactions to their donated organs (Franklin & Crombie, 2003; Lock, 2002b; Sharp, 1995;). Future qualitative research might usefully consider the position and subjective experience of kidney patients in relation to living anonymous donors, in order to understand what effect, if any, the nature of the donation has on a recipient.

Secondly, it would be useful to design and carry out an outcome study as a follow-up to the current one, interviewing altruistic donors after they have donated. By using the same methods it might be possible to further understand the psychosocial aspects of their experience. In particular, I would want to pay

attention to the intra-psychic and inter-subjective aspects of their experience in order to explore the suggestions that I have made in the current study that altruistic donation can be theorized from a psychoanalytic perspective as unconscious communication. This would be a way of measuring the validity of the interpretation.

Lastly, due to time and word limits, it has not been possible to carry out or analyse interviews with medical professionals; the physicians, surgeons, specialist nurses and psychologists who are involved in transplant surgery and who are required to assess, operate on and treat living organ donors and recipients. Their discursive constructions and emotional responses to altruistic donation are of central importance in the process. A further study that includes medical personnel would be of interest in building a more complete picture of approaches to organ donation.

*5.7. Relevance of this study to counselling psychology ontology -
Understanding another's subjectivity*

With this research I have attempted to do what Willig (2005) describes as thinking "...more creatively about how to facilitate alternative subjectivities for ourselves and those we work with" (p33). In a detailed reading of Foucault's theory of how subjectivity is constructed by the individual, Judith Butler (2005) describes how Foucault argues that it is not possible for a process of reflexivity to fully reveal the subject as an object to itself. At this point, Butler (2005) suggests, Foucault's thinking is consistent with the psychoanalytic idea of the unconscious that can never be fully consciously understood. Butler writes; "...to take responsibility for oneself is to avow the limits of any self-understanding, and to establish these limits not only as a condition for the subject but as the predicament of the human community" (2005, p83).

Butler (2005) suggests that there are "epistemic limits" to knowing another person, that demanding a person "give an account" of themselves must fail to some extent in order for it to be true (p43). "When we claim to know and to present ourselves, we will fail in some ways that are nevertheless essential to who we are" (Butler, 2005, p42). I understand this as meaning that it is not possible, nor is it even desirable, to account fully for the subjective experience of another individual, and that to claim to do be able to do so is unethical.

Altruistic donation does not seem to fit with the prevailing clinical discourses on organ donation. "Understanding" the altruistic donor therefore presents us with a puzzle. As counselling psychologists, we struggle in our work to "understand" the subjective experience of our clients. This research has demonstrated that allowing the self to be affected by the other is one way of understanding the experience of another person. This approach to counselling psychology practice and research reflects Benjamin's (1990) theory of intersubjectivity and mutuality. Ultimately, it may be that all that can be concluded from the discourses of the altruistic kidney donors who have participated in this study is that they have chosen to "become undone in relation to others" (Butler, 2005, p136).

As we ask to know the other, or ask that the other say, finally or definitively, who he or she is, it will be important not to expect an answer that will ever satisfy. By not pursuing satisfaction and by letting the question remain open, even enduring, we let the other live, since life might be understood as precisely that which exceeds any account we may try to give of it. (Butler, 2005, p43)

5.8. Practical applications of this research

Throughout this study, the construction of their decision to become altruistic kidney donors has been characterised by conflicting discourses and subject positions, suggesting that even when the donors seem sure of what they are doing, altruistic organ donation is far from straightforward in psychological terms for other people involved. It follows from this that the regulation and practices of altruistic organ donation is similarly far from straightforward. The fact that psychologists are required to play a role in this process poses important questions for our understanding of subjectivity and what this means for validity in assessment. One practical application of this research might therefore be to incorporate some of its findings into assessment protocols for living non-directed donations. This would involve taking what might be considered to be a more open stance to the possible unconscious motivation of the donors, rather than remaining within an existing framework that is discursively bounded by society's prescriptions for what is expected of altruistic individuals.

This study has identified a tension between the current social and psychological understanding of “altruistic” donation that raises doubts about the ethics of enabling donors to undergo the surgery they are requesting. There needs to be a conversation about the intra-psychic needs of the donor that they might be attempting to meet through their action. This would mean allowing people such as doctors, nurses, psychologists and the public the discursive space to consider alternative discourses around altruistic donation than those that are currently available. I have argued that discourses constrain individuals at one of either two poles – the altruistic donor as either mad or saint - and I am suggesting that these discourses need to be opened up in order to acknowledge that the “altruistic” donor may partly be meeting their own needs in a non-pathologising way. In principle, there need not be conflict in both donor and recipient benefitting, in fact, it could be argued to lend greater agency to all parties were this to be acknowledged. Training could be provided that incorporates this approach. In contrast, one radical response to the ideas presented in this study is that “altruistic” (non-directed) donations are stopped entirely in order to avoid the possibility that donors may be inadvertently harming themselves. However, this has important implications for ideas about “altruism” to in society. I am deliberately refraining here from a debate about the nature of altruism itself because I argue in this study that what the participants are doing is something more psychologically complex than can be currently understood through theories of altruism.

From the psychological and discursive themes identified in this study, a significant problem, and therefore a potential solution, lies with the current official and societal designation of this type of organ donation as “altruistic”. This discursive repertoire, which is encoded in policy and practice, carries with it a set of powerful and compelling social values that are both constraining and seductive, and to which it appears that some individuals feel compelled to submit themselves. Paradoxically though, because of the technological nature of their altruistic action, is not just the donors themselves who pay the price for their benevolence, their desire to “help” implicates others in the conflict between the social and psychological experience of altruism.

Separating living non-directed kidney donation from discourses of altruism would mean that it could be constructed in a way that could accommodate a wider range of motivations and subjective experience. If psychological benefits to the donor from altruistic donation can be considered, as well as its wider societal benefits,

this then becomes a subject position available to the donor with a concomitant reduction in conflict. A more nuanced understanding of the donor's motivation, taking into account a more detailed appraisal of the subjective experience of the donor as well as its social constructions would free all parties from the current constraints that altruism places on it, and would mean that a more valid assessment of the needs of donors', recipients and society as a whole could take place. This is another practical application of the current research. To begin with, it would require psychologists to enter the public debate and could take the form of actively engaging with official committees and patient and professional groups involved in organ donation policy, or initiating a specifically psychology-led approach.

The interface between the ethics of the individual, the clinic and society creates a space in which Counselling Psychology, with its willingness to consider individual and social experience in pluralistic theoretical terms, is perfectly placed to intervene. In a recent report, the British Medical Authority supported measures to increase the number of organ donors in England and Scotland advocating the adoption of an "opt-out" approach to organ donation. Increasing the number of organ donors in this way inevitably involves an increase in the role of the state in peoples' deaths. It implies that unless an individual actively opts out of donating, their body effectively becomes the property of the state on dying. The BMA's position is that this remains ethically justifiable, since the consideration given to opting-out by the individual is the same as that which has to be given to opting in, as in the current system. I am arguing that psychology has a role to play in this debate and that as counselling psychologists, we can use our capacity to deconstruct language and feelings, and bear anxiety, as a way of allowing a discursively thicker debate on organ donation, joining the public debate about the extent to which society is prepared to involve itself in the way that individuals are allowed, or choose to die.

This could be extended to other contemporary ethical questions about technology, medicine and the body, and how society assigns value to individual lives and the extent to which death can be managed. This could include, but not be limited to, debates about the ethics of all aspects of organ donation, the legal time limit for abortion, the gestational age at which medicine should routinely strive to keep severely premature infants alive, or whether parents have the right to conceive babies with the expressed purpose of providing genetically compatible body

material for a terminally ill sibling, as well as about end-of-life care and voluntary euthanasia. These are all areas in which a discourse analytic and psychosocial approach might be put to use, in a critical engagement between psychology and the effects of discourses of technology on individuals.

This study has demonstrated the utility of a reflexive, psychological approach to the constitutive power of discourse in public life, and to questions about what we as a society want from the operation of technology through and on individuals. It has shown that using language, ideas and anxiety about “altruistic” donation can be deconstructed and approached from alternative perspectives that are non-pathologising and can contribute to understanding.

Appendix D1 – Research Proposal

**What motivates altruistic kidney donors?
A Discourse Analysis**

Researcher: Julianna Challenor

Supervisor: Susan Van Scoyoc

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Abstract

This study will use Foucauldian discourse analysis to identify the discourses that are used when individuals volunteer to become altruistic kidney donors in a London NHS renal unit. These are the discourses of the donors themselves, and those of the health professionals whose job it is to carry out psychosocial evaluations of the donors. It will consider what implications these discourses have for the subject positions of the individuals involved, and for the practice of clinical assessment of organ donors by psychologists and the exercise of power in that relationship.

Introduction

Organ donation, and increasing the number of donors, is a current concern of the NHS. Over a picture of a seriously ill woman, a national media campaign running in the UK asks: "Would you take an organ if you needed one?" The intended message is clear; most people would probably be willing to accept a donated organ, yet only 27% of people in the UK are registered organ donors (NHS Blood and Transplant, 2010a).

Although practiced outside the UK since the 1990s, altruistic kidney donation has only been legal in the UK since September 2006. Altruistic donation is defined as the anonymous donation of a kidney by a living individual to an unknown recipient (Human Tissue Authority, 2006). In 2007-8, 10 altruistic donations were approved, and in 2008-9 this rose by 50% to 15. These numbers are obviously very small in comparison with directed donations, of which there were 927 in 2008-9 (Human Tissue Authority, 2009)

There is a large shortfall in the number of good quality donor organs compared with people who are waiting for transplants in the UK. Currently, there are 6883 people registered as waiting for a transplant (NHS Blood and Transplant, 2010b). In 2008-9, a total of 2330 kidneys were transplanted from all donors, both deceased and living (NHS Blood and Transplant, 2010b). Patients with end stage kidney disease who do not receive a transplant depend on dialysis to stay alive. Dialysis is more expensive than transplantation and highly disruptive to the lives of kidney patients, who are at risk of mood disorders such as depression (Finkelstein & Finkelstein, 1999). Persuading more people to join the organ donor register, or finding more living donors is therefore a priority for the NHS. However, both directed and non-directed

donation are ethically complex because unlike the typical surgical patient, who consents to invasive surgery that is intended to prolong or increase the quality of their life, donors are healthy individuals consenting to surgery that has the potential to harm them (although the risks are low). This means that psychosocial implications of donating are central to ethical considerations.

Individuals who volunteer to become a living kidney donor to a stranger might be considered to be extreme examples of organ donors, yet the absence of a direct emotional motivation, such as a family member needing an organ, means that these individuals present a unique opportunity for study. It is as if one of the major “confounding variables” in an experiment has been removed. In proposing to research the motivation of such individuals, it is hoped that the current study will contribute to a better understanding of organ donation, why people do it, and how others might be persuaded to. This study will also provide psychological therapists who work with living organ donors, the relatives of deceased donors and organ recipients with a better understanding of a psychologically complex issue.

The aim of this research will be to explore the motivation of altruistic donors. It will take a critical realist epistemological approach. The reason for this is that the assessment of altruistic kidney donors is notable for the fact that unlike directed donation, or other forms of donation such as blood or bone marrow, there is a subtle assumption from the start of the risk of psychopathology. Social constructions of altruism and altruistic donation serve to make health professionals wary. In line with Willig (1998), this study intends to use Foucauldian discourse analysis to question dominant constructions of the concepts and practices of altruistic kidney donation.

Research questions

The following research questions will be addressed in the current research:

1. How do people who want to be altruistic kidney donors construct their decision in terms of the discourses that are available to them?
2. Are expert discourses surrounding altruistic kidney donation different to donors' discourses?

3. What are the implications of any different discourses for the practice of clinical assessment of organ donors by psychologists and the exercise of power in that relationship?

Literature Review

The majority of research into motivating factors in kidney donation has been focused on donors who have a relationship with the recipient; directed donation. Adams et al. (2002) argue that altruistic donation shares many psychosocial features with the decision to donate a kidney to a relative or non-related person with whom the donor has a relationship (eg. a partner or friend). From an assessor's point of view, issues of informed consent and legal capacity are the same for both types of donation. Therefore, in light of the paucity of empirical research on altruistic donation, the proposed study will include in its review the larger literature on directed kidney donation and other types of organ donation.

Additionally, as Arribas-Ayllon & Walkerdine (2008) argue, Foucauldian discourse analysis aims to draw on different forms of text so that discourses and power relations can be compared. This means that both theoretical and research literature should be considered to be a type of "expert" text in the current study and will be included in the analysis. Accordingly, in addition to the theoretical and research literature on organ donation, other relevant literature that informs experts' discourses will also be included. An example of this is the large literature on altruism, with competing theoretical approaches, and a sub-section of this is the literature on altruism in medicine. As a result, the literature review will be integrated into the research, and will be conducted and updated throughout data collection and analysis.

No qualitative research with altruistic donors has been found. Gohh et al. (2000) present a case study of a woman who successfully completed an altruistic donation in the authors' clinic, briefly describing the motivation of the donor but this is not qualitative research and makes no claims for textual analysis. Similarly, Hoyer (2003), a German surgeon, gives an account of his own experience of donating a kidney to a stranger and the considerable opposition he received from his peers, explaining that he considered his act to be part of the tradition of Christian charity. Jacobs et al. (2004) include a section on some of the motivating factors of 49

prospective donors but as the authors do not give any details of an analytic strategy or methodological approach to the data, it is not clear how these were arrived at.

There is some qualitative research with directed kidney donors. Belle-Brown et al. (2008) used a phenomenological approach to explore the experience of 12 directed donors, and found that three key themes emerged in the decision making process. These were; the experience of a loved one's illness and suffering, intra-personal and social factors, and the powerful emotions associated with the opportunity to give someone life (Belle-Brown et al., 2008). Franklin & Crombie (2003) also give a qualitative account of parents' and siblings' decisions to donate a kidney to family members. Using content analysis in a phenomenological framework, Franklin & Crombie (2003) found that although no donors expressed regret for their decision and all described increased self-esteem afterwards, the decision to donate was more problematical for siblings than for parents, which in some cases led to psychological distress. Some siblings expressed regret that the decision had not really been theirs at all, suggesting that implicit coercion meant that they were not able to refuse. A particular strength of this study was the large number of participants – twenty donors - as well as the recipients of the kidneys, who were interviewed.

Since altruistic kidney donation is a relatively new clinical procedure, and is much less common than directed donation, much of the literature is not empirical. Instead, it consists of descriptions of how transplant clinics have developed their assessment procedures for altruistic donors. These have generally evolved from the procedures used for assessing directed donors. Adams et al., (2002) and Jacobs et al. (2004) are examples of this type of article, and describe, in varying degrees of detail, psychological assessment and contra-indications to altruistic donation. The aim of these assessments is to ensure informed consent and capacity, and avoid negative psychosocial outcomes for donors. To do this, they rely on a combination of clinical interviews, personality and psychopathology measures to evaluate whether altruistic donors meet the criteria for psychopathology.

Kranenburg et al. (2008) carried out a careful systematic review of this concise clinical literature on altruistic donation and found that although there are similarities in approach, with five articles describing an interview and psychometric testing, there is no agreement on the best measures or assessment protocols to use.

Links between psychopathology and altruism

Jacobs et al. (2004) suggest that altruistic donation has been traditionally mistrusted by the medical community because of a presumption of psychopathology in altruistic individuals. Roff (2007) discusses the ethical implications of regulating altruistic donation and argues that throughout the 20th century, the dominant moral philosophy, derived from economic theory, has positioned altruism as incompatible with rationality. This, Roff (2007) suggests, is the reason that altruistic donors have been traditionally met with suspicion. Baskin (2009) suggests the possibility of “psychotic altruism”, in an article on his own assessment of a prospective donor, which is when an individual with delusional thinking behaves in extreme ways that deny their own needs (p378).

Quantitative empirical studies are rare. Henderson et al. (2003) used a prospective, hypothetical design to assess 93 individuals who autonomously approached the authors’ transplant centre in Canada offering to donate to a stranger. They employed a series of mental health measures and a clinical interview that they adapted from a validated adult attachment interview. Henderson et al. (2003) found that “suitable” donors were more likely to express a desire to make a substantial improvement in another person’s life with an acceptable level of personal cost, had a consistent spiritual belief system and previous experience of transplantation or medicine. They were also more likely than a control group to be considered to be altruistic by objective standards, so were more likely to have been blood donors, community volunteers and/or be registered bone marrow donors (Henderson et al. 2003).

Henderson et al. (2003) suggest that contrary to assumptions, altruism expressed through kidney donation can be consistent with psychological health. A limitation of this study is the hypothetical design, because altruistic donation was not legal in Canada, and this may have influenced the results. The individuals who agree that altruistic donation is a good thing *in principle* may not be the same individuals who are prepared to complete an altruistic donation.

Landolt et al. (2003) also surveyed peoples’ hypothetical willingness to be altruistic donors and found that 29% of 500 people contacted said that they would be willing (in principle) to be altruistic donors. Those people were more likely to score highly on openness to experience and agreeableness using the NEO-PI. Again, a limitation of this finding is that the results may have been different than for actual donors. There

is support for the findings of Henderson et al. (2003) and Landolt et al. (2003) however. Jacobs et al. (2004) gave a positive account of the motivations of 49 actual altruistic donors at their clinic. As discussed above however, accounts in Jacobs et al's (2004) study appeared to be largely anecdotal, rather than the result of a detailed qualitative analysis.

Positive psychosocial factors for altruistic donation

Adams et al. (2002) reviewed the findings on altruistic donors and concluded that ethically acceptable motives for non-directed donation are; altruism, religious beliefs, a desire to reciprocate to society and a desire to honour an individual who died waiting for a transplant.

Adams et al. (2002) point out that there is no comprehensive understanding of the psychological and emotional impact and motivation for altruistic donation. Rodrigue et al. (2007), support this view and suggest that agreement on the scope of assessments of anonymous donors is currently limited because of a lack of data on psychosocial outcomes for anonymous donors.

In a response to the expansion of the practice in the US, an article by Dew et al. (2007) recommends guidelines based on clinical consensus for the psychosocial evaluation of altruistic kidney donors. The authors suggest that the following factors will protect against poor psychosocial outcome; the absence of psychopathology present or in the recent past, no substance abuse/dependence, knowledge of risks and benefits for donor and recipient, little or no ambivalence, realistic expectations about outcome, a history of medical altruism, a history of reasonable adaptation to life stressors, and support from the family for donation.

"Contra-indications" to altruistic donation

Jacobs et al. (2004) argue that most contra-indications to altruistic donation are the same as for directed donors, such as active grief or severe depression. However, Adams et al. (2002) point out that it is not known whether the psychosocial outcomes for directed donors are the same as for non-directed donors. One small-scale exception to this is by Jendrisak et al. (2006), who followed up seven non-directed donors three months after transplant and found that they all had positive psychosocial outcomes.

Dew et al. (2007) suggest a list of characteristics that they consider to be factors that are likely to contribute to poor psychosocial outcome following altruistic donation. These are; significant psychiatric disorders, either past or ongoing, substance abuse/dependence, limited ability to understand risks and benefits for both donor and recipient, ambivalent or unrealistic expectations, motivation that reflects a desire for recognition or a personal relationship of some sort, family stressors or obligations, expectation of secondary gain, a poor relationship with family or a family that does not support donation.

Methodology

Foucauldian Discourse Analysis (FDA)

Willig (2008) suggests that FDA looks for discursive resources available within a culture, the institutional practices these discourses are bound up in and the implications this has for individuals' experience of subjectivity, material conditions and practices.

Arribas-Ayllon & Walkerdine (2008) argue that individuals ground their claims of truth in their subject positions, which allows them to manage their moral positions. The decision to volunteer as an altruistic kidney donor is essentially a moral one. The intention in the current research is to understand the donors' experience of subjectivity and material conditions in this decision. It is therefore appropriate to explore the subject positions that donors construct for themselves using discourses.

Participants

Selection criteria for participants will be determined by involvement in the altruistic donor programme of the renal unit of the Royal Free Hospital, London. The benefit of this strategy is that it will ensure that the same assessment process is being described, as institutional differences are likely to exist. Conversely, this approach risks limiting the scale of the research, which may result in impoverished data.

Selection of participants will be non-random and purposeful. There will be two groups. The first will be around five individuals who have approached the renal unit of the Royal Free hospital during 2010 indicating a desire to donate a kidney to a stranger. Individuals in this group will be called "prospective donors". It will not be

necessary for donors to be accepted onto the transplant programme for their participation in the research.

Procedure

Prospective donors will be contacted by letter and research interviews will take place after the prospective donor has been assessed by the Royal Free Clinical psychologist and given the results of this assessment. It is possible that as a result of this strategy, prospective donors who are not accepted onto the transplant programme because of psychological factors may also decline to take part in the research study. In order to minimise this likelihood, the donor will be contacted by the researcher around 48 hours after their assessment by the psychologist. This will allow the participant some time to process their experience. It will be made explicit both in writing and in person that the interview is for research purposes only and will have no retrospective bearing on the decision of the assessing psychologist. It's possible that a participant who has been turned down in their application to become a donor will draw on different discourses in an interview and it will be necessary to be mindful of this in the analysis.

A further drawback of this strategy is its reliance on individuals volunteering during the research period. The number of participants is a realistic estimate arrived at after consultation with the hospital's renal psychologist.

A second group of participants, also purposefully sampled, will be "experts" drawn from the hospital's professional staff involved in the assessment of prospective donors. The intention is to represent all the professionals who take part in the assessment process, including a psychologist who carries out the psychosocial assessment, and nurses who provide the initial screening of volunteer donors. It is expected that this group of participants will have less incentive to take part in interviews. If recruitment proves difficult, existing texts from written protocols and prior assessments will be used.

Design

This study will employ a qualitative, longitudinal design, interviewing the participants at two points in time. The approach will be Foucauldian discourse analysis. Willig

(2000) and Arribas-Ayllon & Walkerdine (2008) suggest that texts selected for FDA should allow access to a continuous experience over time.

Text collection strategy

For prospective kidney donors and “expert” participants, semi-structured interviews will be used. Semi-structured interviews are indicated as most suitable for discourse analysis (Parker, 1992). The suggested interview schedules for both sets of participants are in Appendix 1. This will be piloted with a prospective altruistic donor from outside of the Royal Free hospital. Interviews will be recorded on a digital recorder and transcribed in detail.

After the transcripts of interviews have been analysed, participants will be given the opportunity to read and comment in a second interview. Willig (2008) suggests that giving participants the opportunity to challenge or correct the researcher’s assumptions adds validity in qualitative research. There is a risk that this may result in participants withdrawing from the research and this will be allowed for in the timetable. Withdrawal is more likely if participants are not adequately informed about the nature of discourse analysis, therefore it has been made explicit in the information for participants. The second interview will focus on the participant’s response to the analysis of their first interview. This may result in further discourses being identified in which case they will be incorporated into the analysis.

Existing texts

Discourses relating to official policy and regulation of the assessment of altruistic donors will be drawn from documents such as those available on the Human Transplantation Authority website (www.hta.gov.uk). There is material available in the general media, such as articles that have been written on the subject containing interviews with donors. The research literature will also form part of the text to be analysed and will be incorporated throughout the study.

Analytic Strategy

Feasibility – Is Foucauldian discourse analysis an appropriate analytic strategy to answer the research questions?

Analysis of texts will be guided by the stages suggested by Willig (2008) and Parker (1992). In line with Gillies (1999), the current study will use discourse analysis to identify the dominant discourses that both donors and experts use to construct their positions, and the function and effect of these discourses. Willig (2000) suggests that through discourses, subject positions are made available to individuals.

Discourses in use in organ donation are readily discernible. An example can be seen in the current national media campaign that highlights a personal, almost self-interested approach to organ donation by raising the spectre of a loved one, such as a child, who may one day need an organ. This suggests the use of anticipated guilt as a motivating factor. Anticipated guilt is a discourse from social and health psychology and the authors of the media campaign draw on it to achieve their aim of increasing the number of organs available for transplant. The proponents of altruistic organ donation, who emphasise on self-sacrifice, tend to draw on different discourses.

Donor Discourses

The following is an example of discourse analysis relating to the first four stages of the six stages of discourse analysis described by Willig (2008), applied to the text of an anonymous altruistic donor's blog. The writer is in the process of being assessed as a donor (See Appendix 2 for transcript.) The four stages are to identify i) discursive constructions, ii) discourses, iii) the function or action orientation of the discourses, and iv) how the discourses allow the writer to position herself in relation to her decision (Willig, 2008). This example also utilises some of Parker's (1992) steps in his description of the method.

The discursive object in this case is determined by the research question, and is the decision to be an altruistic donor. The donor draws on a moral discourse to construct her decision, in which the needs of others are prioritised, and selflessness is virtuous. This is also consistent with a religious discourse, and contains the idea that "knowing the change it can make in someone's life" (line 82) is "rewarding" (line 83). This religious discourse is evoked when she writes; "please pray that this works out well" (line 77). The donors' reward comes from knowing that someone else has been helped, which is also consistent with the secular, psychological discourse of altruism. This is an example of where contrasting discourses overlap to construct the same "object" in different ways (Parker, 1992).

The fact that she has written the blog suggests an awareness of the attitudes of doubt about her decision, so implicitly refers to a counter-discourse of individualism that is implied by those who question her motivation. This suggests that she is using altruism and morality discourses to justify a decision that many may consider incomprehensible, positioning herself within a framework of morality.

The second discourse she uses is of destiny or fate. She talks about her decision to donate as being inevitable, an irresistible force; she “cannot sit back and deny someone in need” (line 69). It is as if it is part of her essential human nature and not a matter for free will: “I had to put myself forward” (line 45). The function of the destiny discourse may be to absolve her. It suggests that the responsibility for the decision may even be out of her hands. It could therefore serve to put an end to debate because she has no need to question it further herself, and implies that others need not do so either. The decision is final: “So now I am not going to sit back and wait until I die before I can help someone” (lines 73-74).

Finally, when she talks about donation being a safe thing for her to do, both for herself and her family because there is no history of kidney disease, she is using a scientific, rational discourse to demonstrate that she has considered the physical risks to herself. It also draws on the legal discourses of capacity and medical ethics. She is not putting herself in undue danger and her approach to her body is pragmatic and utilitarian, she has spare parts so they should be put to good use: “someone really in need might as well have one of them” (lines 21-22). This discourse allows her to communicate her sanity, to demonstrate that she has considered whether donating a kidney may be personally harmful to her own health and found that it will not. She is positioning herself as a rational, autonomous individual, capable of assessing evidence and risk scientifically. This discourse also allows her to take the subject position of a sane and humane person. She also positions other donors in this way. The discourse, if not the positioning, is likely to be shared by both the donor position and the expert position.

In comparison, the potential recipients of donated organs are relatively invisible in these discourses. They are positioned as victims who are dependent on others for healthy life. This positions people with kidney disease as helpless and has ethical implications for this research, which is discussed below.

Expert Discourses

Altruistic donors are assessed by “experts”; medical and psychology professionals whose responsibility it is to ensure that the donor has the legal capacity to consent to undergo an operation of this sort. Assessments have their theoretical basis in cultural constructions of psychiatric diagnosis and psychometrics; discourses which position the assessors as experts and the donors as patients (Parker et al., 1995).

Expert discourses available in the literature include Henderson et al.’s (2003) use of an adapted attachment interview, suggesting that one of the discourses that experts draw on is attachment theory. Participants who were not considered to be suitable significantly differed in their view of donation as a way of “making a statement against their families” (Henderson et al., 2003, p206).

Challenges and limitations associated with FDA as an analytic strategy

It is evident from the brief analysis outlined above that there are limitations associated with a social constructionist approach to research and FDA. Although the donor’s personal psychological and embodied experience is acknowledged, these are considered to be secondary to a discussion of external, discursive resources (Willig, 2004). Thus compared with a phenomenological approach, acknowledgement of the individual’s agency is limited since it is assumed that people are not ultimately free to determine their own experience of selfhood and subjectivity.

Sims-Schouten et al. (2007) suggest that the issue of embodiment is problematical when taking a strictly relativist approach to research in psychology research. The result of this is that it is potentially disempowering, for an individual if their experience of serious illness such as physical pain is discussed in purely relativist terms. There is a possibility that participants in the current research will be disappointed that their subjective experience has been neglected in the analysis.

One solution to this is to take a critical realist epistemological approach to the research as Sims-Schouten et al. (2007) and Parker (1992) argue. To that effect, the epistemological approach taken in the current study will be that end stage renal disease is a real, material condition, or extra-discursive factor, that is both independent of, and contextualised by, the discursive practices of modern western medicine (Sims-Schouten et al., 2007). This means that all of the practices and

subject positions taken by donors and experts ought to be considered in relation to the extra-discursive factor of kidney disease. This epistemological position will be acknowledged to participants in the written information they are given. It will also be made explicit in person by the researcher during the debrief after the interview.

Secondly, in focusing on the donor and ignoring the recipient of organs, does this analytic strategy neglect and disempower recipients of donated kidneys? This dilemma effectively illustrates why the critical realist position is relevant here. The extra-discursive factors are the material conditions; their illness means that the patient on the kidney transplant list *is* in a less powerful position, there is little they can do other than wait. It suggests that it will be important for the current study to include a discussion of power in the relationship between donor and recipient, in addition to power in altruism and the relationship between expert and donor. Is it important to the donor that they potentially hold the power of life over another individual? This will be addressed in the interviews and literature review. To counterbalance, it is expected that the experience of recipients will be implicitly represented in the expert positions and discourses, since the professionals who work in this field do so with both donors and kidney patients.

Ethical Considerations

What are the potential risks for the participants?

Prospective donor participants may be distressed after an interview in which they're asked to talk about their emotional and family history. As the researcher, I will make a telephone number available for the participants to call me for one week after the interview in the event that they experience distress. Information about aftercare in the form of the participant's GP, NHS Direct and the Samaritans will also be given in the participant information letter and contact information is given. The participants will also be able to contact the researcher if necessary via the Renal Unit psychology office.

NHS ethical approval will be required using the IRES system. Ethical approval will also be required from the Royal Free Hospital's local ethics committee.

Recordings of interviews and transcripts will be kept in a locked cabinet in the researcher's home. Recordings will be destroyed once they have been transcribed.

Transcripts will have personal identifying information removed and personal details of participants will be kept separately, also in a locked cabinet.

What are the potential risks for the researcher?

Interviews with participants will take place in hospital consulting rooms in order to safeguard the researcher.

There are risks and benefits of undertaking research whilst working in the renal unit. As a trainee Counselling Psychologist, I will be counselling dialysis patients. This is likely affect the way I think about and approach prospective donors and will require that I undertake regular reflective practice and clinical supervision and include this in the reflexive sections of the study.

A benefit of being part of the unit means that there will be a source of informed emotional support for me as the researcher and the participants if the research process demands it.

Relevance to Counselling Psychology and practical applications of the research

There are a number of ways in which this research is consistent with the ethos of Counselling Psychology. The theoretical relevance is suggested by Widdicombe (1995, cited in Willig, 1998), who argues that participants redefine themselves and their situations when they take part in discourse analysis, and in doing so they are empowered.

Moreover, this research will attempt to understand individuals who may be positioned outside what is considered “normal” in the dominant culture and this ideographic approach is also consistent with the aims of Counselling Psychology.

Thirdly, Willig (2008) suggests that Foucauldian discourse analysis looks for institutional practices that discourses are bound up in, and the current study will focus on the practice of assessment of individuals by psychologists. Parker (1992) suggests that when we consider assessment in psychology and medicine, we ought to pay attention to the role of power in the relationship between the individuals concerned and between the client and psychology as a whole. Power and the

assessment of clients are of interest to Counselling Psychology, which prizes the client's agency.

This research will have practical applications in renal counselling, as well as for applied psychologists and health professionals working with other types of organ donation. It is hoped therefore that it will be of interest to individuals who provide psychological therapies to living organ donors, their families, and the recipients. It will also provide a discussion that will be relevant to psychologists whose role it is to assess clients, in all settings, not just those who work in the areas of clinical and mental health.

Appendix D2 – City University Ethics Release Form

Appendix D3 – NHS Ethics Review Document

Appendix D4 – Letter detailing amendments for NHS Ethics committee

9, Lyncroft Gardens
Ealing
W13 9PU

Surrey Research Ethics Committee
Education Centre
Royal Surrey County Hospital
Egerton Road
Guildford, Surrey
GU2 7XX

16 June, 2010

Study title: **What motivates altruistic kidney donors? A discourse analysis**

REC reference number: **10/H1109/37**

Dear Mrs Jackson,

Further to your letter dated 14.6.10 detailing requests from the Research Ethics Committee in response to the above application, please find enclosed the following documents:

1. Participant Information Sheet for health professionals (Version 1.1; Date: 16.6.10).
2. Consent form for health professionals (Version 1.1; Date: 16.6.10).
3. Letter of invitation for health professionals (Version 1.1; Date 16.6.10).
4. Revised letter of invitation for donor participants (Version 1.2; Date 16.6.10)

As requested, I would also like to confirm the following recruitment procedures:

(i) Donor participants will be identified by the clinical psychologist who is the department lead, Dr Jeff Cove. Following the first contact, a letter of invitation (version 1.2; Date 16.6.10) and Participant Information Sheet (version 1.1; Date 18.5.10) will be sent to participant. As requested by the REC, contact information for my Academic Supervisor will be given and this is reflected in the version 1.2 of the letter of invitation.

(ii) For health professional participants, I will approach the Manager of the health professional with a request to send the health professional a letter of invitation (Version 1.1; Date 16.6.10) and a Participant Information Sheet (Version 1.1; Date 16.6.10). As requested by the REC, contact information for my Academic Supervisor will be given.

Thank you for considering this revised application.

Yours sincerely,

Julianna Challenor

Appendix D5 – NHS Research Ethics Service Approval

Appendix D6 – Hospital agreement to act as a Patient Identification Centre

Appendix D7 – Letter of invitation to participants



Department of Psychology
School of Social Sciences
City University
Northampton Square
London, EC1V 0HB

8 March, 2011

Re: Altruistic Donor Research Project

Dear,

Thank you for giving me permission to contact you and to invite you to take part in my research project about altruistic kidney donors. I understand that Jeff Cove telephoned you earlier today regarding this.

I have been given permission by the Royal Free and the NHS to carry out this research and can assure you that all your details remain confidential. I do not share the content of interviews with anyone at the Royal Free and the study is completely separate from the assessment process there. The study will be go towards my qualification in Counselling Psychology at City University, London, and will hopefully be used to give people a better understanding of altruistic donation.

The attached information sheet will give you some more information. Once you have read this, if you have any questions, are interested in discussing this research before you make a decision, or you would like to arrange to take part, please contact me in one of the following ways:

By telephone: 07549 499 591

By email: Julianna.challenor.1@city.ac.uk

By letter to: Julianna Challenor, c/o N. Hann, Department of Psychology, School of Social Sciences, City University, Northampton Square, London, EC1V 0HB.

If you prefer, you may contact my academic supervisor, Susan Van Scoyoc, Consultant Psychologist. Email: susanvanscoyoc@mac.com

The interview will be recorded on a digital audio recorder and will take about an hour. It can take place either in your home, or if it's more convenient for you, at City University in Islington, for which your travel expenses will be reimbursed. If you decide that you do not wish to take part, you need do nothing else and I will not contact you again.

Yours sincerely,

Julianna Challenor
Counselling Psychologist in training
City University, London
Email: Julianna.challenor.1@city.ac.uk
Tel: 07549 499 591

Appendix D8 – Information sheet for participants



Department of Psychology
City University
Northampton Square
London, EC1 0HB

5 May, 2011

INFORMATION SHEET FOR STUDY: “What motivates altruistic kidney donors”

I would like to invite you to take part in a research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. This will take about ten minutes. Talk to others about the study if you wish.

Part 1 tells you the purpose of the study and what will happen if you take part. Part 2 gives you more detailed information about the conduct of the study. Please ask me if there is anything that is not clear.

Part 1:

1.1 What is the purpose of the study?

The main purpose of this study is to go towards my qualification in Counselling Psychology called a DPsych. The aim of the study is to look at the way prospective altruistic donors think and talk about their decision; how they explain this decision and their personal reasons for wanting to donate. The type of research that I am doing is called qualitative research.

1.2 Why have you been invited?

You have been given this information sheet because you have been taking part in an assessment to become an altruistic kidney donor. I would like to invite you to take part in an interview and be part of my research. I am hoping to interview around five potential donors.

1.3 Do you have to take part?

The interview is only for my research and is not part of the Royal Free assessment process. It is up to you to decide to join the study. I will describe the study and go through this information sheet. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect your application to become an altruistic kidney donor if assessment is still ongoing.

1.4 What will happen to you if you take part?

I would like to meet with you twice. In the first meeting I will interview you about your decision to become an altruistic kidney donor. It will probably last around an hour

and a half and will be relatively unstructured, like a conversation. The interview will be recorded on a digital voice recorder. In the study, your real name will not be used and any identifying details will be removed.

When I've analysed your interview, I'll arrange for us to meet for a second time for you to tell me what you think of my analysis and to add anything you think we've missed. This second interview will probably take around 45 minutes. The time between the first and second interview will be between two and six months and will be arranged at a time convenient to you.

1.5 What will be done with the data?

Along with interviews from other altruistic donors, I will analyse what we have talked about. I will be looking at the way that you describe things and the implications of certain ways of describing things.

1.6 Expenses

Any expenses you incur in travelling to be interviewed will be reimbursed.

1.7 What will you have to do?

All that I will be asking you to do is to talk to me about what made you decide to become an altruistic kidney donor.

1.8 What are the possible disadvantages and risks of taking part?

Talking about subjects that are very important to us can sometimes stir up difficult emotions. This is normal and things will usually get settle down after a day or two, but if it happens and you feel that you want to talk to someone, there are several things you can do:

1. In the days following the interview, you can contact me if you need to talk through anything that the interview may have raised for you. Please leave a message on the following number and I will return your call as soon as I am able to: 07549 499 591 I can also be reached by leaving a message with the Royal Free renal unit office: Tel: 020 7794 0500 Ext. 37571

2. Your GP will be able to help and you should contact them if you feel as though you cannot cope with distressing thoughts and feelings that you may be experiencing.

3. NHS Direct provides 24-hour telephone support for health worries; Tel: 0845 4647. Website: www.nhsdirect.nhs.uk

4. The Samaritans provide emotional support on the telephone, face to face, or by email, 24 hours a day; Tel: 08457 90 90 90; Website: www.samaritans.org

1.9 What are the possible benefits of taking part?

The information that comes from this study may help improve the way altruistic kidney donation is organised.

1.10 What if there is problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this will be given in Part 2.

1.11 Will taking part in the study be kept confidential?

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2:

2.1 What will happen if you don't want to carry on with the study

You may withdraw from the study at any point and your assessment, if it's ongoing, to become an altruistic donor will remain unaffected. Any interview data that you have given would be destroyed in the event of you withdrawing from the study.

2.2 What if there is a problem?

If you have a concern about any aspect of this study, you should speak to me and I will do my best to answer your questions. I can be contact on Tel: 07549 499 591 or by email: Julianna.Challenor.1@city.ac.uk

If you remain unhappy and wish to complain formally, you can do this with City University. Details can be obtained from:

Department of Psychology
City University
Northampton Square
London, EC1 0HB
Tel: 020 7040 4564

2.3 Harm

This study is covered by City University's Public Liability and Professional Indemnity insurance.

2.4 Will taking part in this study be kept confidential?

Interviews will be recorded on a digital voice recorder. Names will not be used and recordings will be given an identifying number. Recordings will be transferred to CD and stored in a locked cabinet.

The recordings will be transcribed and your name and any other identifying information will not appear in transcripts, ie. Interviews will be anonymised.

The transcripts will only be used for the study described in this information sheet and once the study has been completed and marked by university assessors, recorded material will be deleted. Only I will have access to identifiable data.

2.5 Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Surrey Research Ethics Committee.

This study has received ethical approval from the Psychology Department of City University, London.

2.6 Further information and contact details

If you would like to discuss anything about this research and your participation further, please contact me:

Email: Julianna.Challenor.1@city.ac.uk Phone: Tel: 07549 499 591

My Research Supervisor from City University is:
Susan van Scoyoc, Consultant Psychologist.
Email: susanvanscoyoc@mac.com

Copy to be kept by: Participant.

Appendix D9 – Participant debriefing document



Department of Psychology
City University
Northampton Square
London, EC1 0HB

16th June, 2011

Research Study: “What motivates altruistic kidney donors: A discourse analysis”.

Dear,

Thank you for taking part in the research interview today. I am grateful for your time and value your contribution.

What happens next?

I'll be transcribing the interviews and analysing them. I'm interested in the language and ideas that you have used to talk about your decision to apply to be an altruistic donor.

Your aftercare

Talking about subjects that are very important to us can sometimes stir up difficult emotions for a few days afterwards. This is normal and will usually get better after a day or two, but if it happens and you feel that you want to talk to someone, there are several things you can do:

1. Following the interview, you can contact me if you need to talk through anything that the interview may have raised for you. Please leave a message on the following number and I will return your call as soon as I am able to. I can also be reached by leaving a message with the Royal Free renal unit office: Tel: 020 7794 0500 Ext. 38159. I will be available for one week after the interview.
2. Your GP will be able to help and you should contact them if you feel distressed and as though you cannot cope with any thoughts or feelings.
3. If it's out of working hours, or you do not wish to go to your GP, NHS Direct provides 24-hour telephone support for health worries; Tel: 0845 4647. Website: www.nhsdirect.nhs.uk
4. The Samaritans provide emotional support on the telephone, face to face, or by email, 24 hours a day; Tel: 08457 90 90 90; Website: www.samaritans.org

Who is supervising this research?

My Research Supervisor from City University is:
Susan van Scoyoc, Consultant Psychologist.
Email: susanvanscoyoc@mac.com

If you would like to discuss anything about this research and your participation further, please contact me:

Email: Julianna.Challenor.1@city.ac.uk

Mob: 07549 499 591

Yours sincerely,

Julianna Challenor
Counselling Psychologist (in-training)

Appendix D10 – Participant Consent Form

Department of Psychology
City University
Northampton Square
London, EC1 0HB

Patient Identification Number for this study:

CONSENT FORM

Title of Project: What motivates altruistic kidney donors: A discourse analysis

Name of Researcher: Julianna Challenor

Please initial box

1. I confirm that I have read and understand the information sheet dated 18/5/2010 (version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I agree to take part in the above study.

Name of Patient

Date

Signature

Name of Person taking consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file

Appendix D11 – Semi-structured interview guide

- I'm interested in you wanting to be an altruistic donor, will you tell me about it?
 - What makes you want to do it?
 - Where does the desire to do it come from?
 - Why now at this point in your life?

- Tell me about your family and what it was like for you growing up.
 - Parents
 - Siblings
 - Adult relationships

- What do your family/friends think of your decision?

- Attitude to own body/health.

- Attitude to risks.

- When you think about giving your kidney to a stranger, what feelings accompany these thoughts?

- What has it been like for you to do this interview and talk about altruistic donation with me?

Appendix D12 – Sample interview transcript with coding

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