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Reflexivity in practice: Ethical dilemmas in research with potential living kidney donors

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Abstract
"Ethics in practice" are the ethical dilemmas that arise during the conduct of research. In this article, we describe the ethical issues we faced when conducting an exploration of the experiences of 19 potential living kidney donors, and demonstrate how reflexivity can guide the ethical decision-making throughout the research process. We discuss how we addressed issues of risk of potential psychological discomfort and distress to participants; autonomy and consent; and power imbalance, disclosure and reciprocity. We also address the practical implications of our decisions. Through this discussion of the "ethically important" moments we faced, we aim to spark debate about the ethical and practical challenges facing qualitative health researchers today, and demonstrate how reflexivity can contribute to navigating the "ethical labyrinth" of qualitative health research.

Keywords
data collection and management, ethics/moral perspectives, interviews, organ donation, reflexivity, transplantation

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Ethical conduct is a central tenet of clinical research, and pervades every aspect of the research process (Goodwin et al., 2003). The guiding document setting the standards of research involving humans in Australia is the *National Statement on Ethical Conduct in Human Research* (National Statement). This document informs the design, ethical review and conduct of research and is underpinned by the values of research merit and integrity, justice, beneficence, and respect (NHMRC, 2007a). The National Statement provides comprehensive guidelines on two themes: risk and benefit, and consent. The document defines "risk" as "a potential for harm, discomfort or inconvenience" (p. 15), and states that "research is ethically acceptable only when its potential benefits justify any risks involved in the research" (NHMRC, 2007a: 17). With regard to consent, the guiding principle is that of voluntary participation in research; according to this principle, consent must be based on sufficient and adequate information, and understanding about the research and the implications of participating in it (NHMRC, 2007a).

As part of the "procedural ethics" (Guillemin and Gillam, 2004), researchers must seek formal approval from ethics committees to ensure that the principles of autonomy, privacy, dignity, beneficence and justice underpinning research are upheld in their protocols. Similarly to other countries, in Australia, ethics committees review research proposals involving humans to ensure that they are ethically acceptable and comply with relevant standards and guidelines. All universities and major hospitals in Australia have a formally established ethics committee, and these committees are registered with the National Health and Medical Research Council (NHMRC) (NHMRC, 2007a).

Ethics committees are able to consider 'predictable' issues that may arise in the conduct of research and ensure that researchers have addressed them adequately in their research protocols. However, these formal or procedural ethics are different from what is termed "microethics" (Guillemin and Gillam, 2004), "ethics in practice" or "ethics in action" (Morse, 2007), which are the day-to-day ethical issues that arise throughout the research process (Guillemin and Gillam, 2004). It is these day-to-day ethical dilemmas which are particularly relevant to qualitative research, and they are especially challenging, as they are difficult to anticipate, they arise unexpectedly and spontaneously (Goodwin et al., 2003) and they must be resolved as they occur.

In this article, we reflect on the ethical dilemmas we encountered in our study of the experiences of potential living kidney donors. We also discuss how we used reflexivity – the process through which researchers demonstrate self-awareness and awareness of the research setting (Grbich, 1999) – as a tool to evaluate the research process (Finlay, 2002b). The study is described first, and is followed by a reflection on the ethical issues encountered throughout the pre-recruitment, recruitment and data collection phases as they unfolded. Some of

these issues were difficult to predict and others, in hindsight, could have been at least partly anticipated. A final section discusses the lessons we learned and the implications for qualitative health researchers today. With our candid account, we hope to contribute to the body of knowledge on ethical issues in qualitative research and the challenges researchers face.

The study

Our study was a qualitative exploration of the experiences of potential living kidney donors (PLKDs) as they undergo the assessment process to determine their suitability to donate. As part of their assessment or "work-up", PLKDs undergo a series of medical tests as well as a psychosocial assessment consisting of a session with a social worker, psychologist or psychiatrist (NHMRC, 2007b). We wanted to explore how PLKDs experience this work-up process and the time leading up to the potential transplant operation, and we were interested in the experiences of both those who were deemed suitable to donate and those who were deemed unsuitable.

Our study was informed by the principles of phenomenology, insofar as we were interested in participants' lived experiences (Starks and Trinidad, 2007). We collected the data through semi-structured in-depth interviews consisting of a series of exploratory, open-ended questions; the questions provided a blueprint to guide the interview and the semi-structured format was flexible enough to allow participants to tell their story in their own words and introduce new topics. The interview schedule was iteratively developed, so that topics which were introduced by participants were further explored in subsequent interviews.

We recruited a total of 19 participants through one of the two kidney transplant units in Western Australia. All participants were genetically or emotionally related to the intended recipient; 13 were going to donate directly to the recipient, while six were part of a paired kidney exchange program whereby potential donor-recipient pairs who are incompatible with each other can be matched with other incompatible pairs (NHMRC, 2007b). With the exception of two, all participants had been deemed suitable to donate.

The interviews were conducted between February and August 2013, they had an average duration of approximately 45 minutes, and they were conducted at the participants' convenience either at home or at the hospital, or on the telephone for those living in regional areas. The research team consisted of a Principal Investigator (PI), an Associate Investigator, and the Study Coordinator (SC), who was the person responsible for recruiting participants and conducting the interviews. The study was funded by the hospital's Research Advisory Committee, and we sought and were granted ethics approval from the hospital's ethics committee (reference number 2012-172).

Our ethical dilemmas

As the study unfolded, we noted that our participants were in a position of 'situational vulnerability', a type of vulnerability which is context specific and may be short-term (Meek Lange et al., 2013), and that, in our study, involved participants' personal circumstances and the circumstances surrounding the recipients. As a result, we encountered a number of ethical dilemmas we had not anticipated. These largely occurred during the recruitment and data collection phases. In this section, we describe these ethical issues following a chronological sequence as they arose from the pre-recruitment phase through to the end of data collection.

Pre-recruitment phase

Because we were interested in exploring how PLKDs experienced the work-up process to assess their suitability to donate, we needed to approach potential participants after completion of the work-up so that they would be able to share with us their insights and experiences of the whole process from beginning to end. We soon realized that, for some participants, this recruitment time would be very close to the transplant operation. This triggered our first dilemma: should we have a recruitment and interview cut-off point before the operation? If so, what should it be? How long before the operation? We consulted the literature, but it did not provide us with a satisfactory answer. Most qualitative studies reporting on the experiences of living kidney donors are retrospective and the interviews have been conducted post-donation, from one week (Andersen et al., 2005) to many years after transplant (Crombie and Franklin, 2006; Williams et al., 2007). Studies reporting on experiences pre-donation tend to explore the experiences of donors at different points in time and they do not always report on the time of the interviews (Gill and Lowes, 2008; Sanner, 2005). In their exploration of the experiences of 11 families who had undergone kidney transplantation conducted in the United Kingdom, Gill and Lowes reported that interviews were conducted "pre-transplant" (2008: 1610), but the authors did not specify the time frame. Meanwhile, in her study of the experiences of 39 donors, Sanner (2005) conducted the pre-donation interviews the day before surgery. We found this to be problematic, because evidence shows that the time before transplantation is a stressful period for PLKDs. For example, when Pradel and colleagues (2003) conducted focus group interviews with potential donors, donors, potential recipients and recipients, the authors reported fewer participants in the potential donor and potential recipient groups. This lower participation was due to the short time window between the mailing of the letter of invitation and the date for the transplantation, which led to several potential donors and potential recipients declining to participate "because it was a busy and/or stressful period for them" (Pradel et al., 2003: 205).

After consideration of the literature, and guided by concerns regarding participants' situational vulnerability (Meek Lange et al., 2013), we agreed upon a cut-off point of two weeks prior to transplant surgery; thus potential participants who had completed their work-up and whose transplant operation was scheduled a minimum of two weeks later or not yet scheduled were invited to participate, while those whose transplant was scheduled to take place within the two-week window were not approached. We acknowledge that this was an arbitrary time frame, but it was a compromise between maximizing the richness of the data we were hoping to collect and minimizing the risk of emotional distress to participants.

This ethical decision had two practical consequences: firstly, although we had originally planned to recruit participants after the surgeon's appointment (the last appointment potential donors are required to attend before the transplant operation), we decided to modify our protocol and bring recruitment forward. Thus, we set the new recruitment point after the final meeting at which the suitability of the donor is reviewed by the transplant team (this is the final stage of the work-up process, and occurs before the surgeon's appointment is scheduled). Secondly, as a result of this decision, we had to forego the recruitment of several potential participants whose operations were scheduled within the two-week window.

It is worth noting that, in our study, this critical two-week window only applied to PLKDs who had a scheduled date for the transplant surgery; it did not apply to either participants deemed unsuitable or to those deemed suitable whose operation was on hold because the intended recipient's kidney function was stable.

Recruitment phase

As we began recruiting participants to our study, we realized that recruitment was ongoing for two other studies which also targeted PLKDs at the same hospital. We became concerned that this might cause confusion among potential participants, and that PLKDs might feel overburdened or experience 'research fatigue' (Clark, 2008). This was especially relevant in our study given the characteristics of the sample and the small sample pool – in 2012, only 17 living kidney transplants were performed at the hospital where we recruited our participants (Boudville, 2014). Thus, a meeting between the research team, the renal team's research coordinator and the transplant nurse coordinator was convened and it was agreed that recruitment efforts for the studies would be coordinated. As a result, the PI and SC worked closely with the renal team's research coordinator throughout the recruitment process, ensuring that potential participants were aware of the other studies being conducted and what participation involved in each of them, thus minimizing the risk of confusion.

During this phase we faced another dilemma relating to negotiating consent to participate in the study. Recruitment strategies described in the literature reporting on qualitative studies of PLKDs include recruitment through an invitation letter (Gill and Lowes, 2008), a social worker (Adams-Leander, 2011), via recipients (Crombie and Franklin, 2006) and through an invitation letter with an opt-out slip to be returned if potential participants did not want to have any further contact (Pradel et al., 2003). Because of privacy concerns relating to the disclosure of personal information to a third party and given the study's funding constraints and tight deadlines, in our study we adopted a recruitment strategy similar to that described by McGrath and Holewa (2012) in a study involving PLKDs conducted in Queensland: the PI – a consultant nephrologist at the hospital – made the first contact with potential participants; the PI provided a brief overview of the study and gained verbal consent for potential participants' contact details to be forwarded to the SC. The SC followed up with a telephone call, provided an overview of the study, invited potential participants to take part in the study, and finalized recruitment by mailing an information sheet and consent form to potential participants, and gaining written consent prior to the interview.

The National Statement states that "even where there is no overt coercion or pressure, consent might reflect deference to the researcher's perceived position of power, or to someone else's wishes" (NHMRC, 2007a: 20), further stating that a person should only be included as a participant when their consent is voluntary (NHMRC, 2007a). Despite the fact that the PI did not recruit participants to the study and did not have any involvement in data collection, we were concerned that participants might feel compelled to participate out of deference towards him, especially given that the PI was involved in the medical care of several potential participants.

Guided by our concern for participants' autonomy, the SC carefully negotiated consent with each participant and apprised potential issues, ensuring that participation was voluntary and participants provided free, informed consent. This ethical concern led us to the last-minute cancellation of one interview, after the SC became concerned that the participant showed signs of feeling uncomfortable about the interview, and gave indications of consenting to participate out of respect and deference towards the PI.

Data collection phase

Issues of power imbalance and disclosure were also addressed during the interview process. There is ample literature addressing the power imbalance between researcher and participant during the interview encounter (Ribbens, 1989; Oakley, 1981), and while some argue that a power differential is inevitable (Hammersley and Atkinson, 1993), in this study we implemented some strategies to address this

issue. The SC disclosed her status as a non-health professional; furthermore, she disclosed that she had no information on participants' medical records. This approach proved to be especially relevant in our study, as the SC observed that participants assumed she had a clinical background and was familiar with their medical history. While this approach does not negate power imbalance during the interview encounter, it helped bridge the gap between the SC and participants and build rapport.

Throughout the conduct of the study, we were also mindful of the potential economic cost of participation derived from the petrol expenses and parking fees incurred in driving to the venue of the interview. Thus, when participants chose the hospital as their preferred venue, a date was chosen that would coincide with a scheduled hospital appointment and the interviews were conducted in an office away from the renal unit. Participants who chose to be interviewed at home were appreciative of having that option, and seemed surprised, as they had the expectation that they would need to come to the hospital for the interview; one participant stated that this had been the first time that someone had "offered to go to them".

We incorporated reciprocity to the research process by giving participants the option to receive a copy of the transcript of the interview, providing them with an opportunity to comment on it. It is noteworthy that the majority of our participants (10) requested a copy of the transcript and the feedback received indicates that this was valued by participants. At the time of writing, a lay summary of results is under preparation; all participants will receive a copy of this summary, which will provide them with a further opportunity to comment on the study results and become more actively engaged in the research process.

Lessons learned and implications for practice

In this article, we reviewed the ethical issues we faced as our study of the experiences of PLKDs unfolded. We learned that, despite our best efforts, we faced issues that were difficult to anticipate and had to be addressed as they arose, and, in hindsight, we acknowledge that some of the recruitment issues might have been at least partly anticipated. We also learned that the ethical decisions we made had practical implications, slowing down our recruitment efforts.

Perhaps the biggest lesson we learned is that often there is a tension between ethical considerations and research constraints and requirements. As qualitative health researchers, we are required to comply with formal ethical requirements; thus, we develop ethically-sound research protocols which are underpinned by ethical principles and values, and must seek and obtain ethics clearance from the relevant ethics committee. However, our ethical responsibility does not end there. As researchers, we must be able to recognize those 'ethically important moments' (Guillemin and Gillam, 2004) that arise during the conduct of research. These are

moments when we need to pause and think about the implications of what we are doing, and make decisions which, as we have demonstrated, have practical implications that can have an impact on recruitment and data collection plans. At the same time, we are increasingly operating in an environment where funding constraints often result in tight time frames and limited resources, and we must balance this tension very carefully.

Reflexivity is a cornerstone of qualitative research and has different interpretations: as introspection, intersubjective reflection, mutual collaboration, social critique or discursive deconstruction (Finlay, 2002a). We conceptualized reflexivity in its broadest sense, as the ethical practice of research (Guillemin and Gillam, 2004), and found that this notion helped us identify and address potential issues in the conduct of our research.

We suggest that at a time when researchers increasingly face funding and time constraints, we may be at higher risk of cutting "ethical corners" as we try to balance ethics and pragmatic challenges. As qualitative researchers, we must remember that the practical decisions we make have ethical implications, and, conversely, our ethical decisions will inevitably have practical implications. In conclusion, we suggest that reflexivity is an effective tool to help us navigate the labyrinth of ethically-sound qualitative research, and that more emphasis should be placed on nurturing the ethical awareness of novice qualitative researchers working in today's challenging environment.

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Declaration of conflicting interests

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