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The ethics of doing research with young drug users

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Abstract

Investigations into young people with problematic substance use raise complex issues for institutional ethics committees. The inclusion of people under 18 years old in research requires significant work in preparing applications that will meet the rigorous criteria that human research ethics committees (HREC) operate within (Bessant 2006). Additionally, researching people's experiences of drug use is fraught with all sorts of ethical conundrums because of its potential legal implications (Fitzgerald & Hamilton 1996; 1997; Moore 1993). This paper will discuss some of the complexities of doing research with these populations using my research on the life experiences of young people with problematic substance use as a case study. After I introduce the study, I explain how the philosophical paradigm of 'ethics' translates into practice. Young people and 'informed consent' are discussed; and the paradox of 'confidentiality' when researching illicit activity is explored. I then use the issue of participant payment to illustrate how the policies of frontline services and HRECs are not always in agreement. Following this, I examine the lack of ethical guidelines that protect the researcher and the implications of this lack of regulation. Finally, I explain how I have negotiated these competing definitions and, most importantly, maintained a research practice that respects and benefits the young people participating.

Keywords: Research ethics, young people, informed consent, drug use, confidentiality, researcher protection

Introduction

The argument for this paper came about when, for the purposes of my own research, I was looking to see how other people managed the ethics requirements implicit with conducting applied social research with young drug users. There are several issues unique to this type of research which were, to me at least, unclear. To understand how others have negotiated some of these dilemmas, I sought out the methodologies of other researchers and their discussions on how they balanced the requirements of collaborating agencies with the conditions set by institutional ethics committees. I was hoping to find a precedent which would serve as a 'how to' guide. Instead, this line of

questioning left me with more conundrums than definitive answers. What follows is my experience negotiating these.

The project

My current PhD research seeks to answer the question of ‘how do young people come to experience problematic substance use?’. To answer this, I am working with two youth alcohol and other drug (AOD) services to recruit outreach workers and young people to participate in interviews. The information being sought from outreach workers is largely quantitative, focusing on the social characteristics of their client group. Data from these interviews will be supplemented by statistical data from agency databases and national epidemiological studies. As these methods do not provide personal or identifying information of any individual, they do not raise any significant ethical dilemmas.

In contrast, there are some ethical issues that arise from my intention to conduct in-depth interviews with young people (aged 15-25 years) involved with youth AOD services. These interviews will seek an oral history of young people’s lives from early-childhood to their current situation. While most of my data will come from interviews, there is also an ethnographic element to the project in that I will spend time in the drop in centres and other services where young people and staff ‘hang out’.

My research is based on a pilot study conducted in my Honours research which was similar in design (see Daley & Chamberlain, in press; Daley 2008). The impetus for research into this area came about from my employment as an outreach worker at a youth AOD service. This experience meant that before beginning my research, I had a grounded knowledge of the themes that would arise when empirically exploring

this area. I knew anecdotally that many, if not most, of the young people presenting at AOD services had had lives that were characterised by extreme disadvantage. I was aware that the prevalence of child abuse and neglect was high, and that homelessness was also common.

Having worked intensively with this group of people, I was aware that a result of these life experiences was that these young men and women had a maturity beyond their years. In my pilot study, young people often commented that they felt a sense of empowerment and satisfaction about participating in these interviews. A colleague suggested to me that this was perhaps because a research interview was an opportunity for a young person to voice their life story without judgment or needs assessment.

While the participants felt positive about the interview, I was caught unaware by the effect that these interviews had on me emotionally. Having had experience as a worker, I felt that I would be okay with hearing these life stories. However, spending hours and hours transcribing these evocative narratives took their toll. Being a researcher rather than worker, meant that I was not in a position to be able to offer participants ongoing counselling and support. This left me with a sense of futility which compounded the sadness that I felt about these young people's experiences. Seear and McLean (2008) refer to this as 'emotional labour' and observe that researchers are eerily silent about referring to it.

Ethics

Obviously, in both the pilot study and the PhD, it was essential to have ethics approval from my university and the collaborating organisations. However, I discovered that meeting the needs of both, when they were sometimes contradictory,

was a balancing act that required careful consideration. The essence of these differing views did not imply that one set of guidelines was 'ethical' while the other was not. The issue was that what defined ethical practice in social research was not concrete. This is because 'ethics' is a philosophical concept which HRECs must place into practical contexts and, of course, what is ethical is open to interpretation. Consequently, the translation from concept into context is, at times, distinctly awkward.

All approaches to ethics seek to provide a way to define what the ethical action is but, of course, all beg the question of 'in whose view is this the ethical action?'. Research ethics guidelines are in place to protect and assist the research participants and to maximise positive aspects of their research participation (Barratt, Norman & Fry 2006). Although I am critical of aspects of regulated ethical guidelines; I am not dismissive of them. I agree with Kellehear (1989) who suggests that ethical guidelines should be interpreted as a 'minimum standard' rather than a definitive authority on the matter.

The approach to ethical practice reflected in the current *National Statement on Ethical Conduct in Human Research* (NHMRC, ARC & AVCC 2007) draws on a utilitarian model. This approach defines the ethical action as the one which produces more good than harm. Obviously, what is good and how it is weighted are underpinning philosophical questions which I do not attempt to answer here.

When we seek to apply an ethical framework to social research, as sociologists we are somewhat hindered by our way of thinking. While sociological theories of deviance lead us to assume that what is 'right' and what is 'wrong' are both relative and contextual; in practice we are still bound by the law (Fitzgerald & Hamilton 1997). While ethics demarcates itself from the law, when what is ethical is at odds

with the law we are faced with confounding dilemmas and obligations. This is especially problematic when the law is vague and situational (Bartholomew 2009). For instance, while people under 18 years are legally able to consent to substance use treatment independently, they are still required to gather parental consent to participate in a research interview. Similarly, young people are able to consent to medical treatment; however, they are not able to nominate themselves as organ donors.

Young people and informed consent

In all research, there is the requirement that participants must provide consent. 'Informed consent' is a slippery notion. On one hand, it can be seen as a specific act (consent is given). On the other, Renold et al. (2008) suggest that informed consent is an ongoing dialogue and that the participant is, as they continue to participate in the research, *consenting*. These authors see consent as iterative and open to revision throughout the research process.

When it pertains to young people, the necessity of consent is complicated by competing definitions and practices regarding a young person's ability to consent. This is not a new issue (see Stuart 2001). In recent times, research with young people has been inextricably linked with bureaucracy. As Bessant (2006: 54) observes, 'there is anecdotal evidence that many researchers decide against research about or with under-18-year-olds because the ethics requirements create too much work'.

The extra 'work' created in ethics applications regard a number of criteria that are specific to young people's ability to provide 'informed consent'. These include the parental consent requisite, and where this is jettisoned, one must prove that young

participants have adequate 'maturity' and 'competence' to consent independently. In my study, while those over 18 are able to consent independently, there are extra requirements for those participants under-18 years of age.

Parental consent

The inclusion of young people in research is often avoided because of the mandate that a parent or guardian must provide consent where the participant is under-18. In many research areas, recruiting participants is time consuming and sometimes quite difficult. In social research, recruiting participants is often opportunistic and people are interviewed at the time of recruitment.

The need to gather parental consent complicates research in that it places additional demands on participants. For instance, a young person might be happy to participate in an interview while they are waiting for something or have not much else to do; but to ask them to first take home a form for their parents to sign and return is too much to expect and stymies the research process. Added to this, certain research areas, while not 'risky', are not what young people would want their parents to know that they are speaking with researchers about. These topics might include attitudes about condom use, knowledge of STIs, sexuality issues and prevalence of parental pressure on young peoples study habits. Further, it is patronising to ask a young mum to get her mum to sign a consent form.

So while the need to obtain parental consent is a guideline in place to ensure that researchers do not take advantage of the young, Bessant (2006; 2009) has pointed out that this guideline inadvertently excludes young people from research participation because researchers avoid including under 18s. In my application to the ethics committee, I put forward the argument that it is ethically dubious, if not

downright discriminatory, to exclude an entire group of people from research participation because of their chronological age.

The most recent *National Statement* has introduced some exemptions from the parental consent requisite. The implication is that HRECs can approve research to which only the young person consents where the HREC is 'satisfied that:

- a) he or she is mature enough to understand the relevant information and to give consent, although vulnerable because of relative immaturity in other respects;
- b) the research involves no more than low risk (see paragraph 2.1.6, p18 [of the statement for definition of 'low risk']);
- c) the research aims to benefit the category of children or young people to which this participant belongs; and
- d) either
 - (i) the young person is estranged from parents or guardian, and provision is made to protect the young person's safety, security and wellbeing in the conduct of the research (see paragraph 4.2.5); or
 - (ii) it would be contrary to the best interests of the young person to seek consent from the parents and provision is made to protect the young person's safety, security and wellbeing in the conduct of the research.' (NHMRC, ARC & AVCC 2007, p.56-57)

These exemptions are significant and provide room for researchers to include young people in research without concern about the work created by the parental consent requirement. But, of course, institutional HRECs are typically conservative so one must articulate the argument that parental consent is unnecessary very thoughtfully and this takes time. In making this argument, the questions that one must answer are 'how are we (as the researchers) going to define and measure "maturity"?' and 'what do we classify as "competence"?'.

Maturity

Although maturity and its opposite – immaturity – are relatively broad in terms of definition, the recognition that maturity is gradual and developmental is important. The *National Statement* (2007: 55) articulates that ‘it is not possible to attach fixed ages to each level (of maturity)’ and this allows for people under the age of 18 to be – potentially – recognised as being of sufficient maturity to consent to research participation independently.

Given the ambiguous nature of ‘maturity’, the statement defines four levels which research participants fall within. Rather than attempting to apply fixed definitions, the statement instead acknowledges that young people may be mature enough in some aspects, and not in others. The only level of maturity able to consent independently is defined as:

Young people who are mature enough to understand and consent, and are not vulnerable through immaturity in ways that warrant additional consent from a parent or guardian. (55).

However, rather than providing a concrete description of what maturity is, this definition instead highlights what maturity is not. Although this creates some distinction, it still leaves a large gap for what, precisely, maturity is. A query that also arose to me in this current climate of extreme social control, was whether it is ‘ethical’ for the researcher to be assessing the ‘maturity’ of potential participants. Surely, as the researcher, there is a conflict of interest at play here. I have a need to gather sufficient numbers of participants, would it not be in my own best interests to classify all young people as ‘mature enough’? This, was a separate aside that I did not bring to discussion with the committee.

In my ethics application, I argued that the young people who I will be interviewing have enough maturity to consent independently given that they are old enough to

initiate and consent to substance abuse treatment. Added to this, I put forward that because these young people have often had to navigate the broader service sector and negotiate a world where homelessness is ever present, they have demonstrated a high level of maturity.

Competence

‘Informed consent’ is underpinned by the presumption that the participant is competent to consent. Like maturity, competence is an ambiguous concept that is difficult to specify. Where competency differs from maturity is that a person’s competence to provide informed consent can be increased by implementing various provisions. Bessant (2006) states that there is a need for research ethics to articulate:

‘how researchers can exercise a duty of care while at the same time respecting the young person’s capacity and right to participate in the research without parental permission’ (51)

Bessant goes on to emphasise that:

‘concern about competence does not provide grounds for refusing these basic principles of equality, or refusing young people the right to have a say about matters they have an interest in. Moreover, a commitment to equality does not call on us to treat each person the same.’ (2006: 53)

Therefore, it should be noted that with adequate information and support, we can increase a young person’s ‘competence’ to provide informed consent.

Given the ambiguity in the concepts of competency and maturity, it is worthwhile to consider alternate ways of transferring the information necessary to obtain informed consent. In my study, I had concerns that some of my participants may not be sufficiently literate to understand the plain language statement. To ensure that the information is conveyed, my research design includes that the plain language statement be discussed verbally with each potential participant to ensure that they

have the necessary information available to be able to give informed consent. I have also included contact numbers for various welfare services. A benefit of recruiting from a welfare agency is that I am assured that each participant is linked in with support services that they can rely on for assistance and advocacy. While the need for this as a direct result of the interview is unlikely, having welfare provisions in place ensures that young people are provided with supports to 'competently' make informed decisions. Inclusion of provisions such as these could potentially increase the number of studies approved to conduct research with people under-18 years.

While the inclusion of young people in research is complicated, the latest guidelines have allowed some exemptions to the parental consent requirement which has given me room to argue my case. However, what has made the ethics process of this project doubly difficult is that I am also interviewing young people involved in drug use.

Confidentiality in research about illicit activity

The normal assumption when we carry out research is that participants have a right to confidentiality. However, in subject areas where research data is incriminating, it is especially important to de-identify data. In studies such as ethnography, where de-identification is not entirely possible, the researcher needs to consider competing ethical demands. As Moore (1993) has noted, ethnography into drug use raises all sorts of precarious issues.

When researching illegal behaviour, the notion of research confidentiality is juxtaposed with laws that prosecute those involved in such activity. Although, as researchers, we seek to protect participants from harm, we do not have the legal privilege of confidentiality. In instances where the researcher becomes privy to

potentially incriminating information, if subpoenaed by the court to reveal data sources, the desire to protect participants may conflict with the need to protect oneself.

Fitzgerald and Hamilton (1996; 1997) have highlighted ‘the consequences of knowing’ which saw a research project suspended for six months. A small study into the behaviours of hallucinogen users was funded by a Victorian state government funding body financed from police-seized assets. Although the project was initially approved by their university ethics committee and classified ‘low risk’; the project was later suspended after the researcher made enquiries about the legal requirements regarding confidentiality of their research data. The impetus for these queries came about when a police officer approached the lead investigator with an offer to assist in recruiting participants in exchange for access to information sourced through the research process (Fitzgerald & Hamilton 1996). The researchers wanted to know how they could assure participants of confidentiality when there was no legislation to protect their research records from being subpoenaed. Fitzgerald and Hamilton’s experience illustrates the contentions and complexities with research ‘confidentiality’.

While some instances of ‘confidentiality’ are clear cut – we know it inappropriate to publish a list of participants’ names and addresses – other assurances of confidentiality are less absolute. While I may want to assure my potential participants that information that they share with me will remain confidential I am not legally able to do so.

To avoid placing participants at risk, I have made clear in the consent forms that I can be forced to disclose my records should I be subpoenaed or where I feel there is an imminent risk to someone. In the preamble to my interview, I explain that issues

that are potentially legally incriminating should not be discussed and that participants should not refer to themselves or other people by full name. As I transcribe interviews, I will change all identifying features as I go. Once transcribed, I will destroy the recording. This way of de-identifying information is a way of increasing anonymity and confidentiality to protect participants.

While ethics committees are guided by the *National Statement*; the statement itself has a disclaimer at the beginning:

It is the responsibility of institutions and researchers to be aware of both general and specific legal requirements, wherever relevant (9).

This places the responsibility of being legally compliant with the HREC. Whether or not what is ethical is synonymous with what is legal is the subject for another paper. But the point here is that in defining ‘confidentiality’ for participants, our ideologue of what is ‘ethical’ must be consistent with the absolute authority in the matter – the law (Fitzgerald & Hamilton 1996).

Participant payments: reimbursement or inducement?

Institutional HRECs are cautious about participant payment because it could, potentially, be inducement. The notion of ‘voluntary participation’ sits uneasily with a cash bonus. Participants should not be placed at risk by participating in potentially harmful research because they are broke. This practice also affects research integrity, as where payment is so much that people will forgo the potential risk element in order to obtain the payment, you are likely to see an over-representation of people with a very low SES participating in research and therefore, an over-representation of poor people suffering the harmful results of research.

Although the university was wary about me offering a cash payment of \$30 to research participants, the policy of one of the collaborating agencies is that research participants must be paid. This policy is based in the belief that young people are providing valuable information and should be reimbursed for their time. It is standard practice in AOD research to pay participants and this practice is not waived because of a participant's age (AIVL 2003; Fry & Dwyer 2001; Fry et al. 2005).

However, what must be established, is that while payment should cover a person's time and travel expenses, it should not be so much that it entices a person to participate in research to which they would otherwise be opposed (Grady 2001). I needed to comply with the policies of the collaborating agency, whilst ensuring that I was not being unethical in my research practice. The final outcome was that my university HREC respected the policy of my collaborating agency and accepted that \$30 is enough to appreciate participation, but not so much as to be an 'inducement'.

Who is responsible for looking after the researcher?

While there are guidelines in place to inform HRECs about how to minimise any risk to research participants, there is little that discusses how we can minimise the risks to the researcher. Seear and McLean (2008) observed that the current *National Statement* '...does not adequately explore the question of how best to protect or support the emotional or psychological needs of researchers.' (13).

Although HRECs do take researcher safety into consideration; what informs their ideas of 'risk' are subjective and discretionary. Obviously, they are bound by workplace insurance and compliance matters. However, what both Kellehear (1989) and Seear and McLean (2008) refer to as the 'silent' issues – the ones that involve deeming groups of participants as 'high risk'; or measuring the psychological effects

of research on the researcher – are left for each committee to manage individually. In my experience, members of my university ethics committees have always expressed concern about the researcher as well as the participants. This has encompassed two main issues – the personal safety of the researcher as well as the researcher's emotional wellbeing.

Researcher safety

Members of my university ethics committee have expressed concern about my personal safety when 'in the field'. My institution has requested that interviews be conducted on site at the agencies from which I am recruiting. They suggest that by meeting participants in private environments, I am 'at risk'. Interestingly, in the pilot study that I conducted for my Honours research, this issue did not come to the fore.

Although I plan on interviewing most participants in the counselling rooms of various services, there will be some young people who, for reasons of both convenience and anonymity, would prefer to be interviewed elsewhere. Cafés and parks are likely locations and a small number of people may have accommodation which is visitor friendly (unlike hostels). Young women with children are occasionally afforded public housing, and for these women in particular, an interview at their home is most convenient. Yet the argument put forward by my university committee is that as the researcher, my safety is being placed at risk by doing this.

Given that as an outreach worker in the youth alcohol and other drug field it was standard practice to visit my clients at home, I query whether or not this situation entails a real risk, or whether the expressed concern reflects the committee's

assumptions about young people who engage with substance abuse services. It is questionable whether my safety would be of such concern were I male, older, or interviewing young people who did not publicly identify as drug users.

Emotional wellbeing

Members of the ethics committee have also expressed concern about how I will be supported in research that involves such intense emotional labour. Several members have stated that while they feel that the research is ethically sound in terms of minimising risk to participants, they are concerned about how the research will affect me emotionally. Their concern regards the potential vicarious trauma in researching the lives of people with backgrounds of abuse. The committees have had reassurance in the point that I have worked in the field so that I am aware of the issues that I am likely to face; but they have also wanted assurance that I will be supported by other sources.

Having previously experienced the emotional affects of this type of research, I agree that there is cause for concern. In Honours, I had felt that having been working in the field, I knew what to expect when researching the area. However, what happened was that the transcription process affected me significantly. The interviews themselves were a positive experience, but spending hours and hours sitting at a computer, usually in the middle of the night, listening to these young people's voices and stories left me with a sense of futility. As a worker, when young people share their experiences with you, you are able to take some comfort in knowing that you will be able to see them again; to provide counselling, or support, or a referral, or a hug. As a researcher, I was of no practical assistance. Perhaps – hopefully – I could share their stories with an audience, but I couldn't see these

young people again the next week, and the week after and share their successes and their sadness. I had their stories, but I was not there to actually support them.

In Honours, I was working in a specialist outreach position, while spending every other moment in the day and night researching the same field. Being so constantly immersed in the experiences of people who had suffered so much was, in hindsight, a recipe for feeling a little depressed! This time around I am prepared for this. Knowing that transcribing is likely to affect me is advantageous in itself. Also, working on the project full-time means that I am able to keep transcription to business hours, rather than throughout the night and without other self-care activities. My supervisor has also arranged for me to access debriefing when needed.

What does all of this teach us about doing ethical research?

As Kellehear (1989) has suggested, research ethics guidelines should be viewed as the minimum practice standard; but recognised as not addressing all of the ethical issues that arise in social research. My experience as a youth worker and youth researcher has led me to be reflexive and to continually assess what actions – and indeed inactions – comprise ethical practice and ethical research. My interest in how young people come to experience problematic substance use raises all sorts of ethical conundrums; all of which can, and have been, managed.

While we have a need to protect young people from the harmful effects of research; we also have an obligation to provide them an opportunity to participate (Bessant 2006). In some circumstances, enforcement of the parental consent requisite can be the unethical research action. It may be inappropriate, patronising or both. Likewise, it is important to consider the competence and maturity of potential research participants in order to establish their ability to provide ‘informed consent’;

however, how we can define, let alone measure, either of these subjective concepts is uncertain. Given that ethics guidelines are insistent that participants must be of sufficient competency and maturity, the absence of certainty as to what comprises either of these things is problematic.

Implementing processes to accommodate issues that are foreseeable is important and useful. In my case, verbally articulating the information in the Plain Language Statement helps me to be confident that research participants who lack adequate literacy are fully informed of what they are consenting to.

As I am interviewing a vulnerable group of young people, often about traumatic experiences, I feel that it is important to ensure that participants have access to other supports should they need advice, support or advocacy about anything to do with the research process. Recruiting from welfare services is a useful way of doing this. I have also provided contact information for other free advice, counselling and referral services in my plain language statement.

As the young people who I am working with are a highly marginalised group, I am firm in the view that researchers in this field need to have an understanding of these young people *prior* to interviewing participants. When a researcher displays shock or sadness, disgust or disbelief, young people sense that they are making the interviewer uncomfortable. Young people engage with youth outreach workers because they are people who they are comfortable to share their experiences with. Good workers do not make young people feel stigmatised or ashamed and they do not perpetuate 'victim' identities. Interviewers need to be similar in approach in order for young people to feel comfortable and safe discussing issues that are often confronting, embarrassing and traumatic. Being aware and sensitive to the issues and barriers that many of these young people face is not something which the ethics

committee requests; however, I would argue that it be viewed as a minimum requisite when researching vulnerable groups about such sensitive issues.

Research that involves collaborations with frontline services can create logistical difficulties. The competing ethical frameworks between the youth services and the university raised some interesting questions. That both camps have such regulated ethical frameworks indicates the importance we (rightly) place on being ethical in one's work. At the same time, that both camps had opposing views on what constitutes ethical research indicates that there is still many murky areas that arise when seeking to understand what comprises 'ethical' social research.

Conclusion

In times of increased social control and public liability, institutional ethics committees have enforced detailed procedures to protect participants, researchers and the institution. How 'ethical research' is defined in practice is often unclear and contradictory. While researchers assume that participation must only be with 'informed consent'; what constitutes 'informed consent' is not always definitive. Although the latest guidelines have allowed room for researchers to apply for approval that allows young people to consent independently, this process still requires significant thought and time in preparing ethics applications.

Similarly, our basic assumption that research participants should be assured confidentiality is brought into question when our research targets those who are involved with illicit activity. We cannot assure confidentiality when we may be legally bound to do otherwise. This leaves HRECs to manage such instances on a case-by-case basis, despite guidelines attempting to make the process transparent and regulated. The work in ethics applications is further complicated when the

ethical research policies of collaborating agencies sit in contrast with the values of those sitting on the institutional HRECs.

Committee members of my university HREC has also considered how best to protect the researcher. Although concern about the emotional wellbeing of the researcher is thoughtful and considerate; the suggestion that I am unsafe in private research settings with the young people in my study reflects two negative stereotypes. Firstly, that young people who identify as drug users pose an imminent threat to outsiders; and second, that as a young female, I am unable to identify, avoid, and/or manage potentially risky situations.

Importantly, my university HREC have encouraged the project and have been felt it important that the research go ahead, despite the complexities involved. This is in stark polarity to the common complaint that ethics committees are overly bureaucratic and problematise the research process. I have found members of HRECs approachable and pleased to provide assistance. My institutional committee have sought advice from my collaborating agencies and compromised on key issues. This reflexive, participatory approach was a useful way of disentangling some of the finer points. Most importantly, it enabled compromise which allowed the research to go ahead in a way that was ethical for the young people whilst meeting the needs of the competing ethical guidelines.

However, until legislation is implemented to protect research participants, the ethics of research into illicit activity will still be determined by the law. When researching young people, although the ethics process is currently intensive and incompatible with tight timelines, I suspect that with increasing numbers of researchers interviewing the young, we will see a shift to a more liberal ideologue among those assessing ethics applications and the guidelines in which they are bound. We will

move toward a mutual understanding that protects participants, while at the same time, respects their right to participate in research activities.

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