

## Perspectives and experiences of homeless young people

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### Perspectives and experiences of homeless young people

**Aim.** This paper reports a study describing the experiences and perspectives of homeless young people as research participants.

**Background.** Worldwide, homeless young people are an especially vulnerable group due to their age, socio-economic disadvantage, and stigmatized status, and can suffer from human rights abuses. Researchers and advocates have noted that we know relatively little about the effects of research participation on adolescents in general, and much less about marginalized adolescents such as homeless young people; nor do we know about their perceptions and experiences as research participants. There is a lack of studies reported to help guide the ethical conduct of research with homeless young people.

**Methods.** Individual interviews with 30 street and clinic-based homeless young people aged 15–23 years and two focus groups with a total of 13 additional homeless young people were conducted in a large West-coast city in the United States of America. The study took place between January and June 2003. Interviews and focus groups were tape-recorded, transcribed, preliminarily coded, with final coding crosschecked and verified with a second researcher.

**Findings.** The majority of young people reported positive experiences as research participants in the past. None reported coercive research experiences; however, many stated that they would have liked more information about how the data they provided would be used by the researchers. All participants reported that it was important to be provided with research incentives, and thought that small monetary or pre-paid phone cards were appropriate incentives. They did express concerns that larger research incentives could be coercive and harmful for some homeless young people.

**Conclusion.** Researchers working with homeless young people should seek greater input from them on the overall design of the study, especially concerning the appropriate use of research incentives.

**Keywords:** community, empirical research report, focus groups, homeless young people, interviews, nursing, research ethics

### Introduction

Homeless young people are increasingly recognized as a medically vulnerable population, and there is a growing body of research documenting their multiple physical, mental and social health needs (Rew 1996, Ensign & Santelli 1998, Greene & Ringwalt 1998, Robertson & Toro 1998). There

are many paths to homelessness. In more developed countries, such as the United States of America (USA), the vast majority of homeless young people are running away from intolerable home situations where they have endured neglect, and physical, emotional, and/or sexual abuse (Robertson & Toro 1998). In developing countries, such as those in Africa, South America and South Asia, family

conflict combined with the stresses of migration and extreme poverty push children on to the streets (Green 1998, WHO 2002). Life on the streets, which often includes substance use, survival sex, exposure to violence, and lack of basic hygiene and healthcare, leads many homeless young people to have poor health.

Worldwide, homeless young people (also labelled 'street children' in many less developed countries) are an especially vulnerable group because of their age, socio-economic disadvantage, and stigmatized status, and can suffer from human rights abuses (WHO 2002). Because most homeless young people have had and continue to have a series of harmful experiences with various adults and institutions in their young lives, they can be highly distrustful of adults and institutions. Their understandable trust issues, along with their vulnerable and highly mobile lifestyles, can make doing research with them a challenge. At the same time, it is important to extend research to include this group, especially in programme and intervention evaluation, in order to learn what services are effective in helping them to lead healthier lives (Meade & Slesnick 2002).

While there are guidelines for conducting research with adolescents in general (Santelli *et al.* 1995), there are no clear guidelines for the ethical conduct of research specifically with homeless young people. Such ethical issues include questions over their ability to consent to participation in research, and parameters for mandatory reporting of a young person's disclosure of information on such matters as abuse (Fisher *et al.* 1996a, Meade & Slesnick 2002, Ensign 2003). In many developed and middle-income countries, the legal age of consent and passage into adult status is 18–21 years of age. Younger people legally require parental consent for most medical care and participation in research. However, in the USA in most states adolescents over age 14 can give legal consent for certain aspects of healthcare, such as for reproductive health, and this ability to give consent for medical care is often used as precedence for their ability to give consent for participation in research. Additionally, in many states in the USA, there is common law in terms of which young people under the age of 18 can be given 'mature minor' status and can consent to all of their own medical care and participation in research (Santelli *et al.* 1995). In the United Kingdom and Australia, there is a similar principle called 'Gillick competence', which refers to the perception by healthcare professionals that an adolescent is deemed of sufficient maturity and understanding to give consent for medical care or research participation (British Council 2002, NHMRC 2002).

Researchers and advocates for homeless young people have pointed out difficulties in using appropriate, non-coercive and

non-harmful incentives for research participation. For instance, researchers who have worked with street youth in international settings such as Brazil have stated that it is never ethically appropriate to give such research participants monetary reimbursements because they would be likely to use the money to buy drugs or alcohol (Hutz & Koller 1999). Researchers and advocates have noted that we know relatively little about the effects of research participation on adolescents in general, much less about marginalized adolescents such as homeless young people; nor do we know about their perceptions and experiences as research participants (Fisher & Wallace 2000).

## The study

### Aim

The aim of this study was to describe the experiences of homeless young people as participants in research, including their perspectives and advice on how to handle ethical challenges posed by such research.

### Design

The study design was descriptive, using a focused ethnographic approach, including semi-structured interviews and focus groups (Morse & Richards 2002). In addition, the principal investigator (PI – JE) had previously used a combination of semi-structured interviews and focus groups with homeless young people and found them to be well-liked by the participants and effective in eliciting rich descriptive information on topics similar to the present. The semi-structured were conducted first and analysed, with major findings then shared and discussed further with the young people in the focus groups as a way of validating and expanding upon the findings. The study took place from January to June 2003 in Seattle, Washington, USA.

### Participants

This study was conducted in two street locations known to be popular 'hang-out' areas for homeless young people, as well as the main clinic specifically for homeless young people in Seattle, Washington. This inquiry was part of a larger concurrent ethnographic project including participant observation of the health-seeking behaviours of the young people. The sampling strategy was purposive and sought equal numbers of male and female youths aged 15–23, and street and clinic-based youths based on previous research experience documenting differences by gender and site selection. In

both research sites, people known and trusted by the young people served as intermediaries in recruiting them for the study and helped with screening out any who had been previously or currently were involved in any research by the same researcher.

#### *Interview participants*

Equal numbers were recruited from the two settings. Participants were chosen for inclusion based on their experience as participants in previous research while being homeless and on their willingness to talk about these experiences. The purposive sampling was reflective of the racial/ethnic mix of homeless young people in Seattle. Young people were recruited and interviewed until data saturation occurred. The final sample for the interviews was 30 young people with a mean age of 20 years (range 15–23).

#### *Focus groups participant*

Two mixed-gender focus groups were conducted, one each at the clinic and on the medical van, with a total of 13 participants. The sampling for the focus groups was purposive, with an attempt made to include an equal number of both genders. Participants in the groups had an average age of 19 years (range: 16–23).

### **Data collection**

#### *Semi-structured interviews*

Interviews covered the meaning of the term ‘research’, experiences (positive and negative) of having been a participant in previous research projects, views of appropriate research consent and incentive issues, and recommendations for future research endeavours. A typical research question was ‘What do you think of when you hear the term research?’ A probe for this question was ‘Overall, do you have positive or negative thoughts when you hear the term research?’ The PI conducted the interviews in a private consulting room in the clinic, or in the street in the front seats of a medical outreach van. All individual interviews were tape-recorded and those who completed the interview received a \$10 pre-paid phone card as compensation for their time.

#### *Focus groups*

The focus groups were led by the PI, assisted by a recorder/research assistant, followed a standard focus group format, and were tape-recorded. The focus group guide covered the same topics as those for the individual interviews, with the same research questions and probes. Young people who

completed a focus group received a \$10 pre-paid phone card along with snacks and milk as compensation for their time.

### **Ethical considerations**

Oral consent/assent was obtained from all participants, with information statements signed by the researcher (the term ‘consent’ is a legal term in the USA and is reserved for competent persons over the age of majority; the term ‘assent’ is reserved for the process for legal minors agreeing to participate in research). Written consent/assent was not obtained because the research was deemed minimal risk in nature, and the young people’s signatures would have allowed them to be identified. The requirement for obtaining parental/custodian written consent was waived as many, if not most, of the homeless young people had suffered abuse from their legal caregivers, and attempting to obtain parental/custodian consent in these cases could cause more risk to the young people. Obtaining oral consent/assent from homeless young people for such research is a common practice in the USA. In addition, references made by the young people to specific identifiable research in the past were deleted from the transcripts to further maintain confidentiality and anonymity. The research plan was reviewed and approved by a university human subjects committee.

### **Data management and analyses**

In preparation for more formal data analysis, an experienced transcriptionist transcribed tape recordings of all interviews and focus groups. Transcribed files were entered into the Atlas-ti qualitative data analysis software (Muhr 1997), coded and checked for inconsistencies by the PI. Following initial coding by the PI, the research assistant (NW) independently coded the material and then together with the PI refined the coding. Qualitative data management and analysis followed standard qualitative techniques, and included latent and manifest content analyses, and frequency tabulations (Morse & Field 1995).

### **Findings**

The majority of young people defined ‘research’ along biomedical lines, such as ‘exploring a disease to see what causes it and what cures it’ and as survey research, ‘those school survey things they give you to see what drugs you’re using.’ All thought that homeless young people should be able to consent to their own participation in research without needing parental/guardian consent:

If we're out here taking care of ourselves and our parents don't really have anything to say about our lives anymore, then we should be able to say what we want to do including research. (16-year-old white male, interview on the streets)

The majority reported overall positive experiences as research participants in the past. In the street-based focus group, they talked about enjoying sitting down and talking about themselves and their lives with researchers. These same young people also mentioned that they did not like to complete lengthy forms, either for research or for services; they usually did not read consent forms, but instead asked someone to verbally summarize the content of the forms for them. They talked of many forms having complex terms and long words, and how they did not have the patience to answer a large number of questions on paper: 'I'd rather someone asked me the questions and not make me read a lot of words.'

While reporting overall positive past experiences as research participants, many young people stated that they would have liked more information about how the researchers would use the data they provided. A representative comment from was:

I'm not really sure what happens to what we give them (researchers) after they're finished. I've heard it gets written up somewhere, but I've never seen it. What do they do with it anyway? (20-year-old white female, interview on the streets)

All reported that it was important to be provided with research incentives, and thought that small monetary (US\$5–10) or pre-paid phone cards were appropriate. None reported having had coercive research experiences; however, in the clinic-based focus group, participants did express concerns that larger research incentives could be coercive and harmful for some homeless young people:

Yeah, I think that if they gave kids money donations for research they could use it for drugs and you shouldn't give 'em stuff that could hurt them. So what I mean is it could be like giving them drugs although it's not directly. I heard of one study that gave kids \$60 for the research and one dude used the money for heroin and he almost died. That's not cool. It would be better to give them things like the phone cards, or cards to like Starbucks (coffee store) or Tower Records (music store), or maybe even backpacks, clothing, or food – things we need and that won't hurt us. (19-year-old mixed-race male, focus group in the clinic)

Related to this issue, those in the clinic-based focus group discussed how many homeless young people can be high on alcohol or drugs while surviving on the streets, and may not even know they are participating in research, or 'would mess

up the research results, because they won't know what they're saying while they're using (drugs).'

In response to the question about what types of research were important to carry out related to youth homelessness, many young people recommended topics such as 'knowing what are good services that help us get off the streets'. In addition, most stated that they would like to be more involved in research, including identifying research topics as well as helping to collect data. No differences by gender or site location of sampling were detected for any of research responses.

## Discussion

These results give insights into the experiences of homeless young people as participants in previous research and their perspectives on ethical approaches to conducting research with them. While it is reassuring that most participants had positive views, previous experiences with research and would like to be included in future research, researchers should take note that they also reported that they would like to have the results of research shared with them. As the results of most research studies on youth homelessness are written as either academic journal articles or government planning documents, it is not surprising that the participants never see the results. However, researchers with homeless young people could build into the research a final community forum in order to share the research results in an informal and culturally appropriate format. Including young research participants in dissemination, using interactive formats such as drama performances, can be effective in presenting the research results to the community (Jones 2004).

All participants felt that homeless young people should be able to consent to their own participation in research; however, the research question about this topic did not include probes into their perceptions based on different risk levels of research or younger ages of possible research participants. In addition, we did not include the young people's views on US mandatory reporting requirements for certain disclosed information, such as abuse and suicidal ideation. (As in many developed countries, the US has laws mandating that adults in certain professions, such as teachers, nurses, social workers, and doctors, report cases of suspected child abuse or neglect, or cases of young persons with suicidal or homicidal ideation to the appropriate child protection government authorities for further investigation and intervention). Future research could widen the present study to include presentation and focus group discussion of different consent and mandatory reporting requirement research

### What is already known about this topic

- Homeless young people are an especially vulnerable group due to their age, socio-economic disadvantage and stigmatized status.
- There is a lack of research to guide the ethical conduct of research with homeless young people.
- Little is known about the experiences and perspectives of adolescent participants in research.

### What this paper adds

- Most participants had positive views of and previous experiences with research and would like to be included in future studies.
- Homeless young participants considered that they could consent to their own participation in research without needing parental/guardian consent.
- Homeless young participants recommended the use of non-monetary reimbursements for participation in research.

scenarios specific to research with homeless young people, such as has been done with non-homeless adolescents in the USA (Fisher *et al.* 1996a).

It should be noted that we assumed that our participants were open and honest in the interviews and focus group discussions. We also assumed that offering phone cards and food to participants did not unduly sway their decision to participate, nor did it affect their responses to the questions. Post-research feedback from staff assisting with recruitment of the young people was that the incentives did not encourage young people to participate who would not have done so in the absence of these incentives.

An important finding of the current study is the fact that many participants stated that monetary incentives over \$US 5–10 (4–8€, 2.70–5.50£) could be coercive and harmful to many substance-using fellow homeless young people. Internationally, the guiding ethical principles for remuneration for research are that it should not be based on level of risk involved in the research and should not be so high as to be coercive (Levine 1986, Sugarman *et al.* 1998). However, clear guidelines on what constitutes appropriate and inappropriate incentives for research participation for adult or adolescent research participants do not exist (Fisher *et al.* 1996b). It is plausible that adolescents in general may be more swayed towards taking part in research by monetary reimbursement than their adult counterparts (Petersen & Leffert 1995); by extension, adolescents in poverty or experiencing homeless-

ness might be even more likely to be coerced into research by monetary incentives. Therefore, we recommend that researchers consider using non-monetary research incentives whenever working with homeless young people. However, young people in this study had not been participants in the researcher's past or concurrent research, and so should not have been swayed in their responses about what constitutes an appropriate research incentive.

Not surprisingly, many participants discussed dislike and frustration with long consent forms, as well as survey research instruments that were difficult to read and complete. Most homeless young people in the USA have had their formal schooling interrupted by multiple foster care placements or other physical moves, and many have low levels of educational achievement for various reasons (NAHIC 1996, Calvin *et al.* 2000, Shore 2003, Sawatzki 2004). Therefore, homeless young people as a whole are more likely to have lower reading abilities and comprehension of difficult health and research terms than non-homeless adolescents. This should be taken into consideration when designing research consent and survey forms for use with this group.

### Conclusion

This study was conducted with a limited and self-selected sample of homeless young people from one US city. Important differences for homeless young people in their perspectives and experiences as research participants may exist for this group in other US cities, as well as internationally. In addition, participants self-selected for the study, and those homeless young people who had had previous negative experiences with research may have chosen not to participate. Nevertheless, the results raise considerations to guide the ethical conduct of future research with homeless young people.

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