

# Barriers and bridges to care: voices of homeless female adolescent youth in Seattle, Washington, USA

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Submitted for publication 25 April 2001

Accepted for publication 25 October 2001

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ENSIGN J. & PANKE E. (2002) *Journal of Advanced Nursing* 37(2), 166–172

## Barriers and bridges to care: voices of homeless female adolescent youth in Seattle, Washington, USA

**Aim.** The purpose of this study was to conduct an assessment of reproductive health-seeking behaviours, sources of advice, and access to care issues among a sample of clinic-based homeless adolescent women.

**Background.** Adolescent women are among the most vulnerable and medically underserved subgroups within the homeless population in the United States. Homeless youth are rarely invited to participate in research aimed at improving their access to appropriate health care. Also, the culture in which they live and the personal experience of being homeless are often not addressed.

**Study method.** The research was descriptive, using focus groups and individual interviews with a purposeful sample of 20 female youth, aged 14–23 years.

**Findings.** The women said that they seek health advice from other women, including their mothers even while they are homeless. They reported first trying self-care interventions, and going to clinics when self-care actions no longer worked. They stated that the main barriers to health care were lack of insurance, confusion over consent, transportation problems, lack of respect (from providers) for their own self-knowledge, and judgementalism from providers.

**Conclusion.** Using the concept of cultural competency, the results provide insights into how to improve communication and health care services for these women.

**Recommendations.** Health care providers need to recognize and appreciate the lifestyle, beliefs, and adaptive attitudes of homeless youth, rather than labelling them as ‘deviant’. All personnel who interact with and on behalf of homeless youth must be adequately trained in general knowledge regarding the health of homeless youth as well as in an understanding of the role that culture plays in their health-seeking behaviours.

**Keywords:** homeless youth, adolescent women, health policy, primary care, public health, paediatric nursing, qualitative research, cultural competency

## Introduction

Adolescent women are among the most vulnerable and medically underserved subgroups within the homeless population.

There are approximately 100 million homeless youth worldwide (United Nations International Children’s Emergency Fund [UNICEF] 1989) and between 500 000 and 2 million homeless youth in the United States of America (USA), with

approximately half of these being female (Council of Scientific Affairs 1989, Farrow *et al.* 1992, Ringwalt *et al.* 1998). Poor access to health care, survival sex (trading sex for basic needs such as housing and food), substance abuse and other realities of homelessness place homeless adolescent females at high risk for early pregnancy, sexually transmitted diseases (STDs), and human immunodeficiency virus (HIV) infection (Rew 1996, Rotheram-Borus *et al.* 1996, Ensign & Santelli 1998, Greene & Ringwalt 1998).

Based on a study in Baltimore, MD, shelter-based homeless adolescent women have poorer health status and higher risk-taking behaviours than do domiciled adolescent women (Ensign & Santelli 1998). In the same study, the homeless young women stated that STDs, HIV/AIDS, pregnancy and depression were their main health concerns (Ensign & Gittelsohn 1998). The female youth spoke of environmental safety threats of violence and victimization by adults, as well as racism and sexism in their lives. Female youth reported that mothers and grandmothers were important sources of health information for them even when they were living away from home. They said that the main barriers to the access of health care were lack of insurance, confusion over consent for care, and judgemental staff.

There is a paucity of research on the reproductive health-seeking behaviours, sources of advice, and self-perceived barriers to health care for homeless adolescent females. Homeless youth are rarely invited to participate in research aimed at improving access to health care. Furthermore, the culture in which they live and the personal experience of being homeless often are not addressed. Meanings for everyday circumstances, including health-seeking behaviours and healing, are molded by culture (Chrisman 1990). Culture guides thinking, decisions, and actions of a community in a systematic way through learned, shared and transmitted values, beliefs, norms, and life practices (Leininger 1988).

The culture in which homeless young women live indicates a shared way of life where coping skills are utilized to endure violence, abuse, isolation, and a sense of mistrust in authority figures. Health care for homeless young women is most effectively provided within an atmosphere that supports their ingenuity while incorporating the unique issues surrounding their tenuous social situation (Barry *et al.*, 2002). This may be achieved using cultural competency as the foundation for the provision of health care among adolescent homeless women. Cultural competency is a set of congruent behaviours, attitudes, and policies that come together in a system, agency or among professionals to enable them to work effectively in cross-cultural situations (Cross 1989). Culturally competent care considers both the health care problem of the youth as well as the history, environment, and current

circumstances guiding the youth's behaviour. Cultural competency necessitates a two-way effort: it requires a learning atmosphere where there is an even exchange of respect, appreciation, power and understanding.

In the present study, ethnographic qualitative methods were used to explore the common sources of advice, health-seeking behaviours, and access to care issues of homeless adolescent women in Seattle, Washington. This was part of a larger study that also assessed female-specific health issues and reproductive self-care practices of these same young women, the results of which are reported elsewhere (Ensign 2001). The study addressed these topics using the above-mentioned components of cultural competency.

## Study

### Method

#### *Population and setting*

The study was conducted at the youth clinic at the 45th street clinic. The 45th street clinic is a community health clinic and a health care for the homeless site located in Seattle. The youth clinic targets homeless and at risk youth, aged 14–24 years. (The United Nations definition of 'adolescent', ages 10–24 was used in the study; however, youth under age 14 were not included due to ethical concerns). The clinic is open two evenings a week, and offers allopathic and naturopathic health care, as well as mental health, HIV and substance abuse counseling on site. During 1996, the year of the present study, the youth clinic served a total of 930 youth, with 51% being female, and 68% being Caucasian (12% each for native American and Hispanic, and 7% African American).

#### **Data collection and sampling**

The study design was descriptive, using ethnographic qualitative methodology including semi-structured interviews and focus groups adapted from 'A Protocol for Using Ethnographic Methods to Investigate Women's Health' (Gittelsohn *et al.* 1993). The data were collected at the 45th street clinic during regular youth clinic hours. Only youth who identified themselves as either currently being homeless or having been homeless in the past 12 months were included in the study. All data were collected by one of the two female nurse researchers who were both experienced in providing health care and education to this homeless youth population. The research was approved by the Committee for Human Research at the University of Washington.

Semi-structured individual interviews were done with 20 women with a mean age of 18.2 years (range 14–23 years).

The racial/ethnic mix of the women in the present study was close to that of the clinic population overall. The interviews covered the topics of sources of advice and access to care issues. The interviews also covered the topic of health-seeking behaviours, including who the adolescents seek health advice from and why, and how they decide to stop self-care and seek medical care.

The interviews were conducted by either of the two research nurses in a private consulting room, separate from the main clinic. Health concerns of the young women were addressed by the researchers at the conclusion of the interview, either through individual health education or referral back to health care providers at the clinic. All individual interviews were tape-recorded with care taken not to record personal identifiers. Women who completed the interview received \$5 compensation for their time.

After the interviews were complete and had been preliminarily analysed, focus groups were conducted for more in-depth exploration of identified themes and topics. Three focus groups were conducted with a group of six young women recruited from the individual interviews. The group had an average age of 20 years (range 16–23 years). The sessions were held in a private meeting room upstairs from the main clinic. They were led by the principal investigator, followed standard focus group format, and were tape-recorded. Women who completed a focus group received \$10 compensation for their time.

#### *Data management and analyses*

Interviews and focus groups were tape-recorded, and then transcribed and entered into a personal computer. The data were coded for identified themes. Utilizing the qualitative software program Atlas-ti (Muhr 1997) the coded textual data were retrieved and analysed following standard qualitative techniques, which included content analyses and frequency tabulations.

## **Findings**

The results of the research are reported by the following categories: (1) sources of advice, (2) health-seeking behaviours, and (3) access to care issues.

### **Sources of advice**

There was little variation in the women's responses to questions of whom they most often ask for advice when they had a health problem or concern. Most said they would first ask a female friend, or a female relative such as mother or grandmother. Others stated they would go to the library or

bookstore and read a medical reference book or call an Ask-a-Nurse phone consulting service. Many of the older youth, who had travelled while homeless, reported the nurse phone consulting lines were available in most major cities and worked well for them when they needed medical advice. Two young women shared their practice of asking advice from an herbalist or from herbal reference books. One stated she would seek a medical diagnosis from an allopathic practitioner, and then treat herself by way of the herbal texts.

The women elaborated on how they decided to ask for advice from which sources, and said they would ask their friends since 'they're going through the same things I am', but were also skeptical of friend's medical advice because 'who knows where my friends get their information'. Many of the women spoke of having supportive relationships with their mothers and talking with them often, even if they were currently homeless. Most of the younger women said they had to be careful what they chose to ask their mothers about because of 'getting a lecture or worrying her'. Several of the oldest women in the study said that their relationships with their mothers had improved as they got older: 'My mom's letting go as I get older – she used to get mad when I asked her things.

In a focus group, all of the women agreed that they preferred to ask advice from another woman, be it friend, relative, or professional. One woman said, '...females can understand more where you're coming from and are more sensitive to personal issues'. Several others stated they had attempted to seek advice from their boyfriends or male friends but they '...just didn't get it'.

### **Health-seeking behaviours**

Most of the young women stated that they would first treat ailments that they knew were manageable with self-care. One young woman stated, 'If I start feeling bad, I won't go (to the clinic) right away. I'll try to figure out what it is first and I wait it out awhile'. The women discussed having common illnesses, such as colds or the flu, and seeking self-care treatments like fluids and Tylenol™. Others said that they attempted to seek advice and remedies from alternative sources such as naturopathic pharmacies.

Several women stated that they wished that medical providers would spend more time teaching them self-care practices:

So then I know and I don't have to waste my time going to a doctor when I just know the information and can treat it myself. Because so many times doctors complain about people coming in when they can treat it at home. So it's like, if they would just take the time to

describe it to us and not treat us like we're ignorant, you know, it would be a lot better.

When the women were asked how they decided to stop trying self-care treatments and seek medical care, they unanimously stated sentiments such as the following:

I go to the clinic when I can't go about in a normal manner. When I can't go about life and can't perform my job. When it affects my personality to the point where I can't hide it anymore. Or when it gets unbearable and I just can't take it anymore because I'm so paranoid or worried about what's going on with my body.

In a focus group discussion about health-seeking behaviours among young women like themselves, all reported that homeless young women usually go to the clinic for a health problem as the last resort after self-care treatments did not work. They also discussed gender differences in health-seeking behaviours, stating that homeless young men were even more hesitant to seek care at a clinic. One summed it up with this statement:

Guys are funny. They're not gonna admit they have a problem. They keep it to themselves more. Guys I know just don't ever want to go to the doctor. You know, someone will say to him 'You should go to the doctor', and they're like, 'Oh no, I'm fine'.

### Access to care issues

In both the individual interviews and in the focus groups, the young women conversed frequently about access to care and what helps or hinders appropriate, quality health care. The women's comments were divided into the following categories for discussion: (1) structural issues of the health care system, (2) individual issues of the young women, (3) overall characteristics of the clinic, (4) characteristics of providers, and (5) communication issues.

#### *Structural issues of the health care system*

The young women said they preferred to seek care from a clinic specifically for homeless and at risk youth, but that it was often difficult if they were sick or hurt on weekends or other times when youth clinics were not open. They claimed that the biggest structural barriers to care at many hospitals or clinics not designed for homeless youth were questions over consent for care, being asked to provide addresses and an identification (ID) card, and source of insurance or payment. In a focus group discussion about this topic, one young woman summarized it this way:

So you have to go to a regular clinic and they take forever to register you and they want to know why you don't have insurance and then

they make you sit there another 45 minutes until they call someone to figure out what it is. I've had so many bills from places like that – so many notices. I always told them from the beginning, 'I'm homeless. I don't have an ID. You can't call my parents; they will not say they're my guardians. They will not take responsibility for me. I don't have insurance.' You know – it's like, 'Can you please? I'm bleeding here – can you help me?'

#### *Individual issues*

Several women stated that being physically sick was a potential barrier to seeking health care: 'When you have a fever of 102°F, you're not going to drag yourself on the bus to the clinic.' Many of the women stated that lack of transportation and money were common barrier to health care:

Sometimes I don't have bus fare to get here to get the free ride outta here and I'm stuck and I have no where to go...so it's really hard 'cause you don't have any sort of transportation and there's nothing you can do about it 'cause you don't have the money to get there'.

They also said that lack of social support for seeking care was a common barrier. Having a friend or a partner accompany them to the clinic was an essential component in seeking care. One said:

The thing I run into sometimes is that my boyfriend doesn't take my illness seriously. Unless he's feeling it, he doesn't think it's a big deal. And so it's really hard because I don't want to go to the clinic by myself when I'm really sick.

In a focus group discussion, the women expressed that needing social support to seek health care seemed more important to young women than to young men that they knew. They said they often needed a friend with them 'for moral support', and that they appreciated it when providers gave them the choice of having their friend accompany them into the examination room.

#### *Overall characteristics of the clinic*

The youth spoke of the general atmosphere of clinics being either hostile towards them, 'where they don't even call you by your name – you're just case number such and such', or inviting, where people, 'remember your name when you walk in; they treat me like a real person'. One commented on the fact that 45th street youth clinic staff do not ask for an ID or proof of their legal name: 'I like that, because when I was homeless I didn't particularly feel like being able to be found. The youth also revealed their ability to tell whether or not a clinic respected their privacy and confidentiality by the way clinic staff interacted with them in the waiting room. They said that they preferred it when front office clinic staff would take them aside into a separate room to ask them personal

questions or to give them information instead of whispering it over the front counter. The youth also stated they did not want to be asked to fill out too many forms when seeking health care: 'Forms are too impersonal. I feel like if it's something they really want to know they should ask it face-to-face.' Several women stated they had been curious about their medical charts but were reprimanded by health care personnel when they looked through their charts while waiting for providers. One young woman said, 'It's my chart. It's all about me, so why can't I look at it?'

In a focus group discussion about young women and survival sex and how clinic staff could sensitively approach the topic, a woman summarized the group discussion with the following statement:

When asking these questions, it would be best if the chart was sitting closed somewhere else and it didn't get written in the chart. Because this is something that most women would be a lot more willing to talk about if they're promised it's not going to be on a written record in somebody's office somewhere. It's going to be in my mind and your mind and nowhere else.

#### *Characteristics of the providers*

The main characteristics young women wanted in health care providers were trust, respect, and a nonjudgemental approach. Many young women expressed that they did not reveal information because of a lack of trust in the provider's ability to keep information confidential:

Some people don't even want to talk to the doctors about what their problem is because they're scared that they're gonna talk to this person, this person and this person...and then everybody else is gonna know.

In individual interviews, many women felt they were not respected when providers assumed that they were sexually active and did not believe them when they said they were not. 'Sometimes in clinics, doctors or nurses will really try to talk you into birth control and tell you to stop sleeping around.' In a focus group discussion, the young women all agreed it was a common experience for providers to be 'too pushy':

They try to talk you into the Hepatitis B shot, or this or that. I don't know how many times I need to tell them, 'I will come to you when I'm ready'. It's like you say 'no', and they can't take 'no' for an answer. It's like, they'll say, 'Well, are you sure?' You know, they'll just keep going into it, and it's like, 'I already told you my answer!'

Many of the young women felt that they were treated poorly due to assumed 'ignorance' about health care issues:

I kind of feel like a lot of times they treat you like you're dumb and ignorant and so therefore, they don't need to explain anything to

you...so if they would just tell us what it is and just describe it and not treat us like we couldn't catch the meaning – then it would be a lot better.

The women wanted health care workers to show respect by recognizing their knowledge of personal health care issues and body awareness. In a focus group, an older young woman who had travelled extensively in the US while homeless, summarized it this way:

Well, a lot of the clinics I've gone to have a strange relationship with the patrons there. It tends to be a situation where 'you don't know how to take care of yourself obviously because you're homeless. So this is what you do and don't tell us about your problems because you don't know what's happening.' I mean, I'm very aware of my body and aware of my health issues. And then I go into a clinic and talk to somebody who tells me that I don't know anything, when a lot of times I know more about my specific problems than they do – it makes me not want to go again.

Several young women spoke of knowing female friends who were bisexual or lesbian and who wanted to have the choice of having a gay-positive provider. In a focus group discussion, the women said it was important to have a provider who was genuine and not 'too hip'. One woman explained this with the following example:

They can be totally overbearing, like, 'I am so OK with homosexuality that you could say anything.' and you feel like it's a front, that they're just saying that because they think that'll make you trust them. And most people who have been on the streets know better than that.

In a focus group, the women were asked if the gender of a health care provider mattered to them. They all agreed that for most gynecological issues, they preferred to have a female provider:

Generally, I feel a lot more comfortable with a woman sticking that big metal thing inside me. She's had it done to her before, so she knows how it hurts.

However, this was followed by a long discussion on the pros and cons of the gender of providers. One woman summarized the final group consensus with the following comment:

I think at the outset you're going to be more comfortable with a female, because you're automatically going to have a certain bond with them because they're a woman, too. But like, when it comes right down to it, it all depends on who the doc – who the person is.

#### *Communication issues*

The young women said that two main barriers to good communication between patient and provider were the provider's

use of medical terminology and the giving of conflicting advice or diagnoses to the women. They also noted how the medical belief system of the young woman may not match that of the traditional biomedical understanding of disease. In some cases, the young woman purposefully self-censors her understanding of her illness in conversations with health care providers:

It's kind of like, if they don't want to listen and they don't want to hear what we think, why we have these little secrets, then it's their loss. I mean if they would want to know about some of our beliefs, I know a lot of the kids or I would gladly tell them. But I've tried it before – just lightly touching on it – and they laughed about it and didn't want to listen so I just stopped.

When the young women were asked in a focus group what health care providers may do to help homeless young women access health care, they summarized their main advice by saying: 'Shut up and listen'.

## Conclusion and recommendations

The research findings show the main sources of advice, health-seeking behaviours, and access to care issues of homeless female youth within the cultural context of homelessness. The sources of advice and health-seeking behaviours were similar to those found for Baltimore shelter-based females (Ensign & Gittelsohn 1998), with the exceptions being that Seattle youth talked of using naturopathic remedies and of gender differences in health-seeking behaviours whereas Baltimore youth did not mention these. This could represent regional differences in attitudes and acceptance of naturopathic remedies (Breuner *et al.* 1998). The fact that many young women spoke of the importance of social support in seeking health care points to the need for clinics to recognize and enhance this. For instance, waiting rooms can be made more inviting for friends to accompany the ill young woman, as well as staff encouraging friends to accompany the young woman into the examination room, as appropriate and desired by the patient. This could provide good opportunities for staff to do informal teaching on self-care practices, information that the youth clearly desire.

The research was with homeless young women from a clinic setting in Seattle, Washington. As such, differences may exist for nonclinic homeless youth in the same city, as well as for young homeless women from other cities in the USA. The women in this study represent the average age of the clinic population (age 19), but important differences may exist for women in younger age groups. In addition, the current study was not meant to be an in-depth ethnographic study addressing the culture of female homeless youth. Rather, the study

addressed aspects of their health issues within the larger socio-cultural context within which these young women live.

The words of the young women in this study reveal an innovative, dynamic subculture within the homeless population. Health care providers and service providers may use cultural competency and the feedback offered by the youth as educational tools for their own practice. The core components of cultural competency are self-knowledge and attention to power relations, and these are most apparent through the present research.

Self-knowledge involves the awareness that fundamental differences exist between health care providers and homeless youth. Providers need to recognize and examine their beliefs, opinions and reactions toward both homelessness and adolescence. The youth interviewed clearly expressed a need for providers to understand their situation and their beliefs apart from widespread negative stereotypes about homelessness and adolescent beliefs and behaviours. Self-knowledge can help the provider to recognize and appreciate the lifestyle, beliefs, and adaptive behaviours of homeless youth, rather than labelling them as 'deviant'. This, in turn, fosters effective communication, mutual respect, trust and a nonjudgemental atmosphere.

As evidenced in the interviews, power imbalances are played out in the biomedical clinic setting where the health care provider is an authoritative figure who diagnoses, teaches and treats, while the patient seeks assistance according to her weakness and need (Pinderhughes 1989). As heard in the interviews, homeless youth listen to providers who show them respect, avoid the use of medical jargon, and talk to them on a more equal, rather than a superior level. Providers could build trust by sharing and explaining information in the youth's medical chart with the youth. Being vigilant for situations in which power imbalances exist in the health care setting will enhance the patient/provider relationship.

Providers must be particularly sensitive to the inherent sense of powerlessness that homeless female sex workers and lesbian homeless youth can experience. Homeless female youth who engage in sex work as a means of survival or who are lesbian-identified are at high risk for being victims of power relations. They may be made to feel morally inferior because of the social stigma attached to lesbianism and sex work. Often, they are forced to endure relentless physical and sexual abuse, both violent acts of power-seeking behaviour (Kruks 1991). As mentioned by the young women of this study, sex work and lesbian identification have important health ramifications, but health care providers need to address these issues in a respectful, nonjudgemental way.

Once the provider is able to embrace and integrate the concepts of self-knowledge and power imbalances into his/her

practice, a solid foundation for culturally appropriate health care is secured. Good communication begins with, as one youth put it, 'shutting up and listening'. By listening to the youth's story with a respectful attitude, the provider may begin to explore the presenting problem in addition to the issues that may hinder treatment and prevention in the future. It is important to allow the youth to discuss her knowledge about health, illness and self-care practices. Good listening skills combined with simple explanations create a bridge for appropriate planning and intervention adapted to the youth's strengths and needs.

The need for cultural competency lies not only with the professionals who provide care, but extends to larger networks of health care agencies, policy makers and researchers. All personnel who interact with homeless youth must be trained adequately in general knowledge regarding the health of homeless youth, as well as in an understanding of the role culture plays in their behaviour. Too often policies are made that are inappropriate to the issues and needs of homeless youth. In order to avoid this, policies made for clinics serving homeless youth must include the input of the youth themselves.

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