Life in the margins: Health researchers learn from society's outsiders

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UC Berkeley-UCSF Joint Medical program students Evie Kalmar and Leah Rorvig at the San Francisco Trans March.

The consequences of social stigma can be physically harmful, and even deadly. People who are shunned by our society—due to homelessness, drug use, non-conforming gender identity, or other attributes—generally have much poorer health and higher death rates than those in the mainstream. They may be at increased risk of HIV infection, be more likely to have experienced violence, or suffer from severe mental health problems, for example.

Colette (Coco) Auerswald M.D, M.S. '89 is painfully aware of this fact. A faculty member at the UC Berkeley School of Public Health and UCSF, she has been conducting research among homeless youth for

more than 15 years. Auerswald recalls that in one research project she led, two of the young people in the study died during the six-month follow-up period, out of fewer than 200 being followed.

"That blew us away," she says. "In a six-month period, you don't expect anyone in that age group to die."

Compared to peers who have stable housing, homeless youths are far more likely to engage in high-risk behaviors. They're more likely to have unprotected sex (including sex traded to meet survival needs), have sex with more partners, and use injection drugs. Not surprisingly, they have higher rates of HIV, and homeless young women are almost five times more likely to become pregnant than others their age. Homeless youths are also at higher risk for mental health problems, such as major depression and post-traumatic stress. Suicide is the leading cause of death for this population.

Stages of street living

Auerswald has studied numerous aspects of youth homelessness, including social networks, street culture, HIV risk, and disparities in the experiences of African American and white youths. One of the distinctive features of her research is her use of mixed methods, borrowing tools from both medical anthropology and social epidemiology.

In an early study, she developed a model called the "life cycle of youth homelessness," which she has employed in subsequent research to examine issues such as youth social networks. When young people first become homeless, says Auerswald, "they lose the social networks that they had in the housed world, be they functional or dysfunctional. They lose the status they have as members of a community, and become members of a very stigmatized community. And they also lose the social

capital— the resources that they might have had as members of a community or a family."

According to the life cycle model, those who remain on the streets enter a stage in which they are initiated into the street culture and are taught survival skills by more experienced street youths. These "peer mentors" introduce them to the street economy—a diverse array of legal and illegal activities that range from the innocuous, such as selling crafts, to the more dangerous, such as drug dealing or prostitution. They then progress to a "stasis" mode in which their outsider identity and loyalty to the street community are well established, and their ties to mainstream society diminish.

In stasis, they experience frequent crises, such as being robbed or assaulted or becoming ill. Ultimately, these crises may lead the youths to question their commitment to street life, or bring them into contact with resources that reconnect them to the mainstream world. This propels them into the final stage of the life cycle model, in which some youths are successful in escaping the streets, often after repeated failed attempts.

"Social networks of youths when they hit the street, and when they're leaving the street, include more non-homeless individuals," says Auerswald. During those transitional stages, she explains, it is easier to reach them with interventions. "But when youths are in the entrenched stages, those young people tend to have very few, or far fewer, contacts who are actually housed. Everyone they know is homeless."

Getting an accurate count

Ethnographic research like Auerswald's is critical for the design of effective interventions for this vulnerable population. But she would also like to find out something much more basic: How many homeless kids

are out there? Accurate numbers would help make the case for expanded resources for homeless youth.

"Guess how many young people HUD says there are on the street in Alameda County," she quizzes. The answer: "Thirty-seven," she laughs. "You can see that many in about twenty minutes walking down Telegraph Ave.!"

HUD, the U.S. Department of Housing and Urban Development, is aware of the inaccuracy of its estimate, says Auerswald, and wants to do something about it. But until now, there hasn't been a way to arrive at a better number, and no city in the world has an accurate count of its homeless youth population.

That's why Auerswald is excited about a project called YouthCount!, which aims to adapt public health methods used in HIV surveillance—such as social networking and mathematical modeling—to survey and estimate the number of homeless and unstably housed youth in San Francisco. YouthCount! has wide support from government and non-government organizations that serve youth and is currently in the process of securing funding.

Jess Lin M.P.H. '10, Auerswald's research coordinator, shares her enthusiasm. "One of the things I hope YouthCount! will do is to expand the definition of homeless youth, to show that there is a diverse set of youth in that population and that different resources are needed for them. It's not just the grimy street kid in the Haight that everyone thinks of when they think of a homeless kid. And even your grimy street kid in the Haight has a lot of different reasons for being there, and there are lots of different possibilities for providing services."

A new generation of aid

As director of research training for the UC Berkeley-UCSF Joint Medical Program (JMP), Auerswald leads the master's program in health and medical sciences for 48 students on the Berkeley campus and oversees their mentoring. Students in the rigorous Joint Medical Program spend three years at Berkeley earning a master of science degree, followed by two years at UCSF, where they receive their medical degrees. Auerswald herself is a graduate of the program.

Among the current JMP students is Lis Powelson M.S. '12. "Lis and I kind of fell into each other's arms when she first came in, because she'd been doing a lot of work with injection drug users, which, of course, is a population that totally overlaps with the population that I'm obsessed with—so we knew right away that we wanted to collaborate on some level," says Auerswald. Alex Kral Ph.D. '00, director of the Urban Health Program at the San Francisco Regional Office of Research Triangle International, served as Powelson's mentor for her master's work.

Just a few of the 3,100 clients served by Larkin Street Youth Services each year.

Another JMP student drawn to a stigmatized population is Leah Rorvig M.S. '12, who chose to work with transgender women. "I was very excited to work with Leah," says Auerswald, "because transgender health is really an area where there's very little research, and the disparities are completely out of control." Rorvig was mentored by Stephen Eyre, an anthropologist and professor of pediatrics at UCSF and associate adjunct professor in the JMP; and Jae Sevelius, co-principal investigator of UCSF's Center of Excellence for Transgender Health.

A focus on female meth-users

Before entering the Joint Medical Program, Powelson worked in a methadone clinic at San Francisco General. Not everyone is cut out for that kind of work environment, but she loved the experience and found it deeply rewarding. "You know, things were always a little bit nuts, but that keeps life interesting—and it's really satisfying when things work out and you've been able to help someone," she says.

When injection drug users come to a clinic, they may have any of a wide assortment of medical problems, such as HIV, viral hepatitis, cellulitis, abscesses, and overdose. Dermatologic problems are common. One of the side effects of methamphetamine is a feeling that insects are crawling on the skin, which can lead a person to pick and scratch at the skin. Members of this population frequently delay seeking medical attention because of mental health problems, difficulty keeping appointments while under the influence of drugs, discrimination in the health care setting, or other factors.

For her master's thesis, Powelson chose to examine unmet non-emergency health care needs among women in San Francisco who use the highly addictive drug methamphetamine. Most research on methamphetamine users has focused on men; few studies have focused specifically on access to health care services for women meth-users.

Powelson's study included 298 women, all of whom were 18 years or older, had at least one male sexual partner in the past six months, and reported using methamphetamine in the past 30 days. Almost half were African American and one-third were white. Most were unemployed, and more than half were homeless. HIV-positive women were not included in this study because their health care needs are so different from other women's.

Face-to-face interviews with the women revealed sobering statistics about their unmet health care needs. Sixty-nine percent reported needing care for a chronic condition; for nearly a third of them, their need was unmet.

In terms of dermatologic care, 35 percent of the women reported a need; of those women, two-thirds said that need was unmet. And when it came to women's preventive care, 92 percent reported a need, with nearly half of them reporting the need as unmet.

A key finding of Powelson's research was that women who reported having a health care provider or caseworker had lower odds of having an unmet need for care. This suggests that regular contact with a health professional could motivate these women to seek care and could help expand their access to health care.

"What really mattered to people is feeling like they had someone to go to. For a med student and a doctor, that's really important. It makes you realize how meaningful your relationship with your patient is. If they don't ever come in, you can't help them," says Powelson.

Trans women face discrimination, intolerance

Rorvig had long been interested in women's and gender studies, but it was her experience volunteering for Maitri, an HIV/AIDS respite and

hospice facility in San Francisco, that sealed her commitment to working with trans-gender women. She was especially influenced by a friendship she developed there.

"I had a patient named Rosa who was a trans woman, and we became very close," Rorvig recalls. "We would go for walks; we would go to the mall; and I helped her move a lot of stuff from her SRO into Maitri once it became clear that it was in fact the end of her life and she was not going to be recovering.

"I got to meet a lot of her friends, many of whom were also trans women, and I was just very inspired by her story. She was kind of a trans rights activist herself, and she educated me about a lot of trans issues and about a lot of intimate partner violence and discrimination that she had been through. Rosa had AIDS—and AIDS is unfortunately extremely prevalent among people who are trans."

A transgender woman is someone who was born male, but who self-identifies and lives as a woman, regardless of whether she has had surgery or taken hormones. Discrimination against trans women is intense: For example, 90 percent of trans women report discrimination, harassment, or stigma in the workplace. In terms of health, transgender women are disproportionately likely to be HIV positive, and approximately one-third have attempted suicide. Nearly one-fifth have been refused health care due to their gender status. And 28 percent have delayed or postponed needed medical care out of fear of harassment or discrimination.

For her master's research, Rorvig focused on the question: What are the negative health care experiences of transgender women in San Francisco, and how have they responded to these experiences? She recruited study participants primarily at transgender-focused clinics in San Francisco. The 25 interview subjects ranged in age from 29 to 66; 48 percent of

them were white and 36 percent were African American. The rest were another race or mixed race. Many reported histories of alcohol or drug abuse, homelessness, sex work, and/or a positive HIV status.

"The single most common complaint I heard about health care was that receptionists, nurses, and physicians refused to use the name or pronouns that a particular transgender person requested," wrote Rorvig in a blog about her research. "Many of the transgender women I interviewed told me that they would verbally correct health care professionals who used the wrong name or pronoun—but that the health care provider still wouldn't necessarily honor the patient's request." Participants described these incidents, which often occurred in front of other patients, as deeply humiliating.

Some of the experiences the women reported were being unable to obtain surgical referrals or find psychiatric services, being denied hormone therapy, and being forced to use a men's restroom. They responded to these negative experiences by avoiding certain facilities, providers, or health care in general; and/or not disclosing their gender identity. More proactive responses included discussing their concerns with the individual or with a third party; pursuing formal complaints; and/or seeking out transgender-focused clinics.

"Unfortunately, many of the women had a very low expectation of health care," says Rorvig. "They had experienced so much discrimination already in their lives that when they went to the health care setting, they went there essentially already expecting that they were going to be discriminated against and have a hard time. As someone who is a young aspiring physician, it is very sad to hear that a patient is already coming to you with low hopes of what you can do for them, and even the level of respect you are going to treat them with."

Rorvig recommends that everyone who works in the health care setting,

no matter their role, participate in gender sensitivity training. In addition, she believes health care facilities should implement formal processes for transgender patients to report negative experiences, and follow up on those reports.

Understanding, courage, hope

Despite the grim realities and serious health inequities that exist for stigmatized populations, researchers like Rorvig, Powelson, and Auerswald are optimistic that further research, tailored interventions, and compassionate health care can improve heath outcomes for people outside the mainstream. They're heartened by successes they've witnessed and courageous individuals they've encountered while doing this work.

"During the course of conducting the interviews, many interviews made me sad, upset, or angry," reflected Rorvig in a blog post. "I heard countless stories of hardship, including stories of sex work, prison, childhood abuse, intimate partner violence, and suicide. However, there are also many stories of healing, personal transformation, evolving self-love, and truly caring partners, physicians, nurses, and therapists."

Auerswald tells the story of Isadora, a homeless young woman she met through her work with the San Francisco nonprofit organization Larkin Street Youth Services. Isadora had left a violent home where her safety was in jeopardy and had landed on the streets.

"She'd taken it upon herself to help other young people who were also homeless," Auerswald remembers. "She had a sort of emergency kit she would always carry around, and she was like a one-person outreach program helping other kids, even though she herself was homeless."

When a community advisory board was formed for a national network to

study HIV/AIDS risk in youth, Isadora was approached to be an advocate for her homeless peers. Auerswald asked Isadora to put together a short CV for her application to serve on the advisory board. "I said, 'It doesn't have to be a big deal, just whatever you can put together,' knowing that that was kind of crazy to even ask a homeless kid for that.

"And she came in—this was the coolest thing—she came in, and she said, 'This is a CV of where I'm going to be in a year.' So instead of a CV telling me what she'd done, she was giving me what she was going to do and what her CV was going to look like in a year. And it was really, really impressive." Isadora's goals focused on earning certifications and gaining tools that would allow her to continue to help her community. "She joined the community advisory board," says Auerswald, "and then she actually did all those things."

Isadora eventually got off the streets. She relocated to another region of California and is now a pastry chef and a mother. Last Auerswald heard, Isadora was thriving. Auerswald is convinced that the support Isadora received from Larkin Street Youth Services played a critical role in enabling this young woman, who had experienced family violence and homelessness, to grow into a healthy adult.

"I think we really focus on the kids who trip and fall," says Auerswald, "but Larkin has hundreds of stories of kids who leave the street successfully, and I think we don't hear those stories enough. So to me, Isadora is a really inspiring story—and she's not the only one."

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