

RESEARCH METHODS IN HEALTH COMMUNICATION

Principles and Application

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(Babbie, 2004, p. 190). Kindig and Stoddart (2003) more specifically define population health as “the health outcomes of a group of individuals, including the distribution of such outcomes within the group” (p. 380). Some health issues are relevant to specific populations, groups, or segments of the population, for example, overrepresentation of a group with a particular disease or differential access to prevention or treatment for a specific group. The National Institutes of Health (NIH) created the Division of Special Populations to strengthen their “commitment to ensuring the health and well-being of children, adults, families, and communities by addressing and eliminating health disparities through the participation of diverse populations in biomedical and behavioral research within the United States and abroad” (NIH, 2012). Further, the NIH highlights population segments within particular research areas (e.g., vulnerable populations within alcohol health or cancer control). Some of these groups are stigmatized, and the following sections define stigma and stigmatized populations.

Some segments of the population are considered stigmatized because of an identifying characteristic, studied under the label “stigma.” This characteristic may manifest as a mark or a deviation from a prototype (see Jones et al., 1984). Goffman (1963) is credited with early conceptualizations of the notion of stigma by focusing on how the reaction of others spoils normal identity, and he defined stigma as an “attribute that is deeply discrediting” (p. 3). Goffman (1990) identified three primary sources of stigma. The first source includes visible deformities of some kind (e.g., scarring, physical manifestations of anorexia, leprosy, obesity). The next stigma source includes personal or social aberrations (e.g., mental illness, drug abuse, alcoholism, criminal behavior). The final source of stigma, “tribal stigma,” represents traits that deviate from what is considered normative for a particular group (i.e., ethnic group, nationality, religious group; see Rush, 1998, for social stigma).

Goffman’s work, although well cited and useful as a research framework, is not well formulated for use in health contexts. More specifically for health, Leary and Schreindorfer (1998) described how individuals are stigmatized to the extent that their identifying traits or characteristics lead to avoidance or rejection from others, and their view is rooted in interaction and perception of others. They suggest four stigma characteristics that can be better utilized to consider methodological challenges for health research: individuals pose a threat to others’ health and safety; deviate from group standards; fail to contribute; and create negative emotional reactions in others.

In their conceptualization, developed for the context of HIV/AIDS stigma, Leary and Schreindorfer (1998) highlight the effects of multiple sources of stigma (i.e., more than one stigmatizing trait/characteristic), stigma attribution, and social contagion. They identify the concept of “master status” that arises when multiple factors coalesce to intensify stigma and therefore increase the negative effects of stigma. Considerable research also addresses the effect of

METHODOLOGICAL CHALLENGES FOR HEALTH RESEARCH WITH STIGMATIZED POPULATIONS

Kathryn Greene and Kate Magsamen-Conrad

Health researchers continue to study an ever-widening range of stigmatized populations, providing valuable information for health prevention, treatment, and utilization. This chapter focuses on how best to adapt methodologies for research with stigmatized groups. We begin with one distinction: stigma that emerges as a research theme during a study and stigma as a component of the sampling plan. This chapter focuses on the latter. In certain studies, some but not all participants report stigmatizing experiences, yet, in some of these studies, population segmentation is not a driving impetus for the study. This type of stigma research is markedly different from cases where a specific group is sampled in order to investigate a phenomena related to a uniting stigmatizing factor. This chapter examines the challenges researchers encounter when they choose to focus on stigmatized populations, as well as recommendations for addressing those problems. It begins by defining *population* more broadly, and then narrows to define stigmatized populations. The chapter continues with conceptualizations of stigma and stigmatized populations, before turning to four recommended methodological practices and final comments.

Stigmatized Populations

One issue that affects research broadly, and health communication research more specifically, is sampling the particular population of interest. Although some fields are dominated by college student samples and associated limited generalizability, researchers increasingly conduct studies using sites such as schools, organizations, hospitals, clinics, medical offices, and service organizations. A research population is a collection of individuals who have some consistent characteristic or trait defined as “the theoretically specified aggregation of the elements in a study”

attribution on stigma; that is, the degree to which the stigmatized individual is perceived to be “responsible” for the acquisition of their condition (e.g., DeJong, 1980; Levine & McBurney, 1977). Researchers may also study partners or family of people with a stigmatized condition or those who work with stigmatized populations (see AIDS volunteers; Frey, Query, Flint, & Adelman, 1998) and should be aware that stigma may “rub off” onto these groups (see “courtesy stigma” in Leary & Schreindorfer, 1998; Alzheimer’s patients’ caregivers in Blum, 1991).

Stigma often creates a sense of “us versus them” that may be used to bolster identity, studied within the model of social comparison (Taylor & Lobel, 1989) or downward comparison theory (Wills, 1981). To cope with uncertainty-related stigma, people may compare themselves with others. For example, Derlega, Greene, Henson, and Winstead (2008) had people with HIV read vignettes manipulated to test social upward affiliation and cognitive downward evaluation processes for other HIV patients’ physical and psychological status. The researchers reported that participants negatively evaluated the patients doing poorly physically (downward comparison) and would avoid patients doing poorly psychologically; however, they also found that the participants wanted to affiliate with patients doing well physically. Another study of these comparison phenomena interviewed people who trade sex for drugs, referred to as “skeezers” ($N = 200$) were interviewed, including the “johns” who traded crack for sex and the women. The first finding was that the men believed that women who trade sex for crack are at the bottom of the social hierarchy (and cannot transmit disease to higher social members). Another finding was that men who used condoms—and many did not—did so to increase social distance. This study illustrated how one group denigrated another group engaged in markedly similar behavior (trading crack and sex), yet this comparison was one-sided: the women described the interaction in economic terms but reported little power in condom negotiation. Overall, these comparison theories demonstrate how people cope with stigma in part by seeing themselves as superior even to similar others. Along with theories of social comparison, Leary and Schreindorfer’s conceptualization of characteristics of stigma and other stigma-related phenomena allow researchers to better plan and execute projects with stigmatized populations. The next section reviews research within populations that have been stigmatized historically.

Examples of Stigmatized Populations

Stigma research transcends disciplines, methodologies, and national borders. Scholars from medical and social sciences (including psychology, anthropology, sociology, social work, public health, and communication) investigate stigma. Some of this research clearly fits into one of the three primary sources of stigma derived from Goffman’s work or Leary and Schreindorfer’s more specific

health stigma conceptualization. For example, researchers have studied stigma related to visibility or creating negative reactions of others, such as with obesity (e.g., Lawrence, 2010; Teixeira & Budd, 2010), including in Germany (Sikorski et al., 2011), and physical disability (e.g., Bang, Armstrong, Hetz, & Latimer, 2010; Kwong, Chung, Cheal, Chou, & Chen, 2012), including in Canada (Bahm & Forchuk, 2009). Homosexuality may be considered within the framework of deviating from group standards or social aberration. Perceptions of homosexuality may be confounded by disease-related stigma (e.g., HIV, see Grandall, 1991; e.g., Cain, 1991; see also stigma of children with lesbian mothers, Gershon, Tschann, & Jemerin, 1999; suicide and transgender stigma, Clements-Nolle, Marx, & Katz, 2008), including research with men who have sex with men (MSM) in China (Neilands, Steward, & Choi, 2008) and Taiwan (Wang, Bih, & Brennan, 2009). Other examples of social aberration or deviating from group standards may include the stigma associated with alcoholism (Keyes et al., 2010), illicit drug use (Palamar, 2012), criminal behavior (Schmittker & John, 2007), or a combination of these (Room, 2005). The distinctions between sources of stigma may be less applicable as a frame because the sources of stigma frequently overlap, and elements of a “master status” (Leary & Schreindorfer, 1998) affect manifestations of stigma. Therefore, rather than review stigmatized populations from the perspective of stigma source, the following sections review examples of research with stigmatizing conditions.

Mental Illness-Related Stigma

Mental illness is highly stigmatized and encompasses a wide range of conditions such as schizophrenia, depression, post-traumatic stress disorder (PTSD), and dementia. Researchers study mental illness stigma (see Herman, 1993; Shaw, 1991), including with Arab participants (Dalky, 2012a), and in Europe (Evans-Lacko, Brohan, Mojtabai, & Thornicroft, 2012) and India (Tirupati, Rangaswamy, & Raman, 2004). Schomerus et al.’s (2011) review of research on mental illness attitudes found increased public knowledge/literacy about mental illness and increased acceptance of mental illness treatment. However, they found no evidence of reduction of stigmatization of people with mental illness (see also Dalky, 2012b, for a review of mental illness stigma intervention trials).

In the past decade, increasing research in the United States has focused on the mental health of veterans returning from deployment. Depression, PTSD, and substance abuse are common in military populations, especially among soldiers returning from combat (American Psychiatric Association, 2012); these effects also have an impact on military families, including spouses. Much of this research on veterans focuses on PTSD. The U.S. Army Office and Surgeon General define a PTSD case as “an individual having at least two outpatient visits or one or more hospitalizations at which PTSD was diagnosed” (Fischer, 2010, p. 2). A combined diagnosis figure (across deployed and non-deployed soldiers) is

88,719 diagnosed cases in all branches of military service between 2000 and 2010, with the highest concentration among the Army (Fischer, 2010). This figure must be considered an underestimate, given the pressure in military organizations to avoid mental health labeling. Mental illness stigma is “especially pronounced in the military, where the pervasive culture is one of mental and physical toughness, pushing through the pain” (Office of the Vice Chief of Staff (Army), 2012, p. 69).

Military populations may be particularly affected by stigma within the context of help-seeking behaviors (e.g., Hoge et al., 2004; see also Hooyer, 2012). The heightened stigma acts as a barrier to pursuing or maintaining care or therapy and thus would inhibit research. Nearly two-thirds (60%) of military members believe that seeking help for mental health concerns would negatively affect their careers (American Psychiatric Association, 2012). The military supports anti-stigma campaigns specifically designed for military populations (e.g., Real Warriors, <http://www.realwarriors.net>), yet mental illness stigma remains in the military, and, more broadly, in the United States and other countries. The following section explores a second stigmatized population well represented in the literature: physical illnesses.

Physical Illness-Related Stigma

Considerable research also investigates stigma related to specific health or medical conditions. Much of this research examines stigma related to sexually transmitted infections (STIs) such as HIV/AIDS (e.g., Florom-Smith & De Santis, 2012; Sowell & Phillips, 2010), including several meta-analyses (see Logie & Gadalla, 2009, for a meta-analysis of HIV and health and demographic correlates of stigma; Smith, Rossetto, & Peterson, 2008, for a meta-analysis of HIV stigma, social support, and disclosure). Other topics include hepatitis C (for a review, see Paterson, Backmund, Hirsch, & Yim, 2007) and behaviors associated with STIs, such as with male sex workers in Bangladesh (Khan, Bhuiya, & Uddin, 2004), or sex workers and injection drug use in Scotland (Bloor, Leyland, Barnaid, & McKegany, 1991). However, research in this area also examines other issues related to health and stigma, such as infertility in the United States (Steuber & Solomon, 2011), the Middle East (Ahmadi, Montaser-Kouhsari, Nowroozi, & Bazargan-Hejazi, 2011), and Ghana (Donkor & Sandall, 2007; Miall, 1986); chronic pain (Goldberg, 2010); and epilepsy (Schneider & Conrad, 1980), including epilepsy in Zambia (Atadzhanov, Haworth, Chomba, Mbewe, & Lano Birbeck, 2010).

Stigma related to a physical condition is a central concern in health management. Golden, Conroy, O'Dwyer, Golden, and Hardouin (2006) conducted clinical interviews at a hospital with 87 patients awaiting treatment for hepatitis C and discovered a strong fear of illness discovery as well as social isolation and rejection. They also found that perceptions of stigmatization were higher among

persons who had contracted hepatitis C through injection drug use and contaminated blood transfusion (for hemophiliacs) than for those who did not know how they contracted the disease. These findings are consistent with Leary and Schreindorfer's (1998) notions of attribution and blame and the source of the disease.

Attribution issues, such as blame for method of disease contraction, are common among stigmatized illnesses, especially STIs such as HIV and hepatitis C. In some instances, the health of the patient is compromised because of beliefs about their degree of “fault” in acquiring their illness. For example, some health practitioners stigmatize persons with hepatitis C, in part because of the associations with drug use (see Corrigan, 2004). This behavior is consistent with reports of medical personnel who refuse to treat HIV+ patients. One emerging area of stigma research is with lung cancer and cancer stigma. Some people who disclose that they have lung cancer report being asked, “Were you a smoker?,” similar to questions in response to sharing an HIV+ diagnosis, such as “How did you get it?”. These questions also focus attention on how a condition was contracted (see Leary & Schreindorfer, 1998). For some receivers, perceived patient responsibility is key in responding to disclosure of a health diagnosis (see Greene, Derlega, Yep, & Petronio, 2003). People who engage in behavior that could lead to risk are more stigmatized than those termed “innocent victims,” who are viewed as having no role in their diagnosis/infection (see Leary & Schreindorfer, 1998).

Patients devote tremendous energy to avoiding these types of stigma, and report stigma is one of their greatest concerns. Many patients choose not to share with others to avoid stigma (e.g., hemophiliacs, adoptees, or parents with children having lice). People also avoid telling others about stigmatized medical procedures (e.g., abortions or cosmetic surgery). Even physicians who perform abortions and clinic staff often do not widely publicize this practice.

Race/Ethnicity and Group Stigma

Researchers have extensively investigated the stigma surrounding race/ethnicity (e.g., African Americans, Latinos, Native Americans), much of which is relevant for health research, such as health disparities. Race/ethnicity disparities are rampant in American healthcare. As an example, even controlling for factors such as health status, insurance, income, and disease severity (Smedley, Stith, & Nelson, 2003), elderly Latinos have higher rates of diabetes and disability than elderly Whites (Wallace & Villa, 2003), and elderly African Americans report more chronic health conditions than elderly Whites (Centers for Medicare & Medicaid Services, 2000). These disparities may also have implications for treatment-related attitudes and help-seeking behaviors (see Brown et al., 2010). For example, Matthews, Selligren, Manfredi, and William (2002) reported that African American cancer patients' embarrassment with cancer stigma was as high as was cancer-related fear.

A variant of group stigmatization research focuses on population segments that are stigmatized for reasons such as extreme poverty, homelessness, or living in remote areas. Research explores Appalachian stigmatization (e.g., Jones, 1997; Latimer, 2006; Zaheer et al., 2011), for example, as it relates to human papillomavirus (HPV) vaccination appraisals (Smith & Parrott, 2012). Other research focuses on the stigma of poverty itself (e.g., Mickelson & Williams, 2008; Reutter et al., 2009; see Waxman, 1983, for a review). For example, Collins (2005) conducted interviews with women from low-income families who expressed a common theme of feeling that others “looked down on them.” This stigmatization is even more pronounced for those who utilize public assistance (e.g., Kerbo, 1976; Stuber & Kronebusch, 2004) or the homeless (e.g., Roschelle & Kaufman, 2004; Snow & Anderson 1993). Researchers have also investigated the intersection of poverty stigma and AIDS/HIV stigma as a barrier to care or treatment adherence (see Coetzee, Kagee, & Vermeulen, 2011), poverty stigma and mental health stigma in Uganda (see Ssebunnya, Kigozi, Lund, Kizza, & Okello, 2009), and poverty and HIV stigma in Tanzania (Amuri, Mitchell, Cockcroft, & Andersson, 2011) and in Zimbabwe (Campbell et al., 2012).

Multiply Stigmatized

Some research examines individuals at the intersection of several different sources of stigma that may compound difficulties with research due to the intensity of the stigma (see Leary & Schreindorfer, 1998). For example, Hartwell (2004) compared the issues of mentally ill persons in the criminal justice system that had or were struggling with substance abuse (“dually diagnosed”) to mentally ill persons involved with the criminal justice system. Hartwell reported that individuals battling both mental illness and drug abuse stigma were more likely to be homeless, violate the terms of their probation, and recidivate.

Researchers should attend to the presence of multiple forms of stigma that can confound and compound both participants’ experiences and research participation. Leary and Schreindorfer (1998) described this as “master status,” and others have referred to “double disclosure,” when one person shares a diagnosis and also (by choice or not) shares another stigmatized trait. For example, in order to share their HIV status, some people with HIV must also disclose homosexuality, injection drug use, or infidelity. In these cases, sharing the information becomes a kind of dialectical “double-edged sword,” where participants may be seeking to access support yet the sharing exposes them to potential negative outcomes.

Lessons for Research with Stigmatized Health Populations

This chapter focuses on methodological considerations and adjustments researchers should make when studying stigmatized populations. Based on the

existing research on stigma and our team’s research, four recommendations are proposed to consider when working with stigmatized populations. These include consideration of language use, threat to reputation, legal status, and illegal behaviors. The recommendations include review of best practices and features to avoid, supplemented by examples from published research or our research projects. We begin with the first recommendation, caution surrounding language use.

Language Use

Researchers working with stigmatized populations should have heightened awareness of how language is used in all stages of research projects, from recruitment through data collection, analyses, and presenting results. Because of the very nature of their status, stigmatized populations may have very strong reactions to use of specific labels. More obvious examples include the terms “faggot” or “dyke” or derogatory racial, ethnic, or religious references (e.g., “nigger,” “WOP,” and “kyke”). Researchers should note, however, that the very nature of in-group dynamics and identification may lead participants to embrace these terms and utilize them during interviews and focus groups, in a process similar to Leary and Schreindorfer’s (1998) description of “stigma avowal.” We caution, however, that, even if participants use a particular term and have reframed it, researchers should be wary of adopting parallel language and using these terms. Use of particular terms by members outside of a community or group—even if the researchers are generally viewed positively or as members of the same group—can backfire and damage relationships (and, potentially, the quality of data). Risks include participants withdrawing from research, avoiding participation generally, and/or responding in socially desirable or perhaps shallow and limited ways.

We have encountered people choosing to identify themselves in particular ways through labeling. First, health researchers increasingly study men who have sex with men (MSM), and some of these men vehemently reject the labels “gay,” “homosexual,” “bisexual,” and “MSM.” Some of these men—for example, heterosexually identified, married, African American men we interviewed in the southeastern United States—described their sexual behavior with men as “just playing around” or a “way to release stress.” These “behaviorally bisexual” men did not acknowledge the sexual acts as relationships but would discuss their sexual behavior; these men emphasized being married and having children as why they were not part of “that group,” rejecting the terms MSM, gay, or bisexual. Thus, some members of this group use certain markers to reject specific labels and avoid potential stigma.

Perceptions of group labels may be especially intense for stigmatized groups, leading to recommendations that researchers be sensitive to participant preferences. In our interviews with women who have sex with women (WSW), we encountered similar cases where people rejected the term “WSW” for lesbian,

and others who rejected both “lesbian” and “WSW,” despite being in a same-sex relationship for more than 10 years (some of these women strongly identified as “bisexual”). Related to these challenges is sensitivity to terms used to describe same-sex partners (i.e., “partner” versus “husband”/“wife”). Partners are crucial in many aspects of health research, not limited to sexual health but also more broadly for social support for a wide range of health conditions where behavior changes are recommended (e.g., cardiac or diabetes patients). The inconsistencies currently created by varying current national and state marriage and civil union laws add tension to an already loaded topic, and researchers may choose to ask participants “Are you in a relationship?” and “How do you refer to him/her?”

Another emerging example is related to transgendered participants (historically “LGB,” now commonly referred to as “LGBT” or “LGBTQ”). When interviewing a participant in sexual transition and/or who presents androgynously or with physical or social markers of both genders, researchers may have difficulty determining which pronoun to use. One participant we interviewed described how hurtful it was that some healthcare staff referred to him as “her” repeatedly, even after specific requests. Although the participant perceived that many staff at this location were sensitive and adapting, some staff appeared resistant to using language other than “legally defined biological gender.” This kind of illustration provides an opportunity for studying factors that affect transgender people’s utilization of health services beyond perception of stigma. In similar cases, one previously successful approach is to ask the participant how s/he would like to be referred (“What name would you like to be called?” and/or “Do you like to be referred to as ‘he’ or ‘she’?”). In our research, this issue has also arisen when interviewing drag queens. In one instance, it was important to refer to the participant by stage name and as “she” when presenting in that identity (i.e., in costume); on follow up, the participant self-identified as “he” and by his birth name rather than performance name.

Finally, our last example is where people misuse terminology related to diseases. We see this repeatedly in our HIV disclosure research. One African American woman described how language use caused her to withdraw and not share with others: “My husband died from AIDS in the early ‘80s. And so automatically, you know, they going to say I got it, if I tell them or not, you know, ‘She got the AIDS.’ It is always ‘the AIDS,’ it’s never HIV.” Participants may be hurt or frustrated with lack of education related to some diseases, but they also seek to avoid stigma. Researchers should recall that the original acronym for acquired immunodeficiency syndrome (AIDS) was “GRID” (gay-related immunodeficiency disorder), despite the presence of heterosexual patients even at the outset of the epidemic. Similarly sexually-transmitted disease (STD) became sexually-transmitted infection (STI), focusing on “infection” rather than using the more emotionally charged term “disease.” Changes in terminology occurred in the sexual assault community, where many issues including stigmatization lead to underreporting of this crime (Egan & Wilson, 2012).

Individuals once commonly labeled “rape victims” are now referred to as “sexual assault survivors.”

Language is a reflection of group values, and effective researchers will immerse themselves in the environment and observe/listen prior to engaging in any type of formal research that would include key informant contact, interviews, surveys, or even focus groups. This kind of reflection is important at early stages, including with recruitment and flyers: researchers are unlikely to recruit effectively if they are using the wrong labels (and, in some cases, if using any labels). Our team regularly uses key informants (members of the stigmatized group) to review recruitment material, scripts, surveys, and interview and focus group protocols. We increase the levels of research material review when participants are multiple stigmatized. Also, we caution that some “key informants” may be more active or open with their condition and may not best represent the population of interest.

Threat to Reputation

Because of the very nature of their status, stigmatized populations may be concerned about threats to their reputation or others finding out either about a health condition (e.g., STI) or some other stigmatized information. This concern may lead stigmatized participants to avoid research altogether or be especially sensitive about location, recording, or note taking. As one example, our team conducts interviews for people with HIV and sexual minorities in coffee shops, nightclubs, and religious institutions if requested by participants, even though most of this research occurs in private offices at AIDS Service Organizations (ASOs). Some participants report that, if they were seen in a specific building in a community such as the AIDS service organization or the public health department, “then everyone would know.” For some of these participants, these avoidance strategies included traveling to different cities or counties to receive treatment and services. The choice of location can increase participant comfort but can also introduce challenges such as maintaining privacy (booths close together at a diner) or noise interfering with audio recording (e.g., at a nightclub or restaurant). Researchers should reflect on how the use of an ASO as location, or a gay bar or public health department, for example, results in oversampling people using these particular resources and underrepresents avoiders who may be the population of interest.

Another example that we have encountered related to threat to reputation is hidden information that may be revealed during the research, such as a participant with multiple sexual partners whose primary partner (e.g., wife or husband) is unaware of the other’s sexual behavior. At times, both participants may be in a research program (i.e., being interviewed), and the staff must be extremely careful not to inadvertently share the partner’s information. We separately interviewed a couple where one described their relationship as “I see us buying a

house together this fall," yet his partner reported, "I'm not sure where this relationship is going or if we'll be together in six months." A more amusing example involved interviewing couples in which one had a heart condition about how they share information and reinforce the patient's behavioral changes (e.g., increase exercise and modify diet). In this instance, the wife proudly described how her husband (the cardiac bypass patient) was now walking for an hour every morning. The husband, however, separately described that each morning he puts on his sneakers, leaves the house, goes several blocks away to buy a newspaper and spends 45 minutes reading on what he described as "a lovely park bench." It may seem obvious that interviewing this couple separately was important, but we would recommend a combination of separate and couple interviews if the focus is on relational dynamics affecting health. For this couple, the joint interview portion of the study also provided valuable information where they clarified perspectives of the other's narrative.

A large pharmaceutical company in the northeastern United States banned smoking not just in their buildings but also within their physical property; smokers cannot smoke outside the buildings or in parking lots. The company also implemented widespread programs for decreasing employee smoking, in addition to encouraging other health benefits such as cholesterol screenings and weight-loss programs. Some employees have successfully quit, yet, for others, there is a great deal of pressure to hide any evidence of smoking or tobacco use. In this kind of case, interviewing tobacco users through this company (unless former tobacco users) is likely to create challenges if interviews occur on site.

Many phenomena are "hidden" to protect people's reputations from stigma, and this occurs for employment and in families where people seek to avoid loss of job or perhaps child custody. For example, some websites offer strategies for concealing anorexia (see Harshbarger, Ahlers-Schmidt, Mayans, Mayans, & Hawkins, 2009), and smoker stigma remains high (Graham, 2012). Extensive research exists on sharing for recovery in Alcoholics Anonymous, yet there remain millions of alcoholics in the United States alone, many of whom hide their drinking patterns (see Schomerus et al., 2011, for a review). A final example is widespread underreporting of sexual harassment (McDonald, Charlesworth, & Cerise, 2011; Vijayasiri, 2008) when people may fear job loss or injury to career path.

Researchers should be cautious with choosing locations and contacting participants, whether at work or even at home (especially if the partner is unaware). Recommendations include using audio-recording rather than videotaping, or taking notes rather than recording the conversations. Make conscious decisions and ensure participants know that they are being protected. Although sometimes an unpopular recommendation, researchers should work with Institutional Review Boards (IRBs), which may have useful and creative suggestions for protecting participants. Overall, researchers should consider the potential effects of the research on employment, spouses, and families.

Legal Status

If researchers are interested in specific populations (e.g., undocumented immigrants, people not paying child support, parolees), there are additional considerations. The very nature of their status may put some populations at risk of legal consequences which vary by country but could include deportation or arrest. The stigma attached to some of these groups includes portraying them as a drain on the public and not contributing to society (see Leary & Schreindorfer, 1998). For example, undocumented workers are abundant in the United States but they may be reticent to participate in research. These millions of undocumented workers may be relevant for studying a wide range of health issues such as utilization of healthcare services, vaccination, or prenatal nutrition.

For some research, any form of linkage with the research project could put the participant at risk. For example, a researcher may be interested in children's health coverage in families where one participant owes child support, yet identifying the "delinquent parent" could put the individual at risk of incarceration. In these cases, researchers should request waivers of written consent, which removes the requirement for documentation such as a recorded signature, yet retains the elements of consent. Where needed, researchers should also obtain federal Certificates of Confidentiality to ensure that the risk posed by participating in the research is minimized (e.g., no list of names/addresses is tied to the study, even for payment). Researchers should take maximum precautions to keep confidential any list or data that includes identifying information. It is possible that the risks to participants (and, potentially, to researchers) outweigh the potential gain from the research. In some countries, certain behaviors, such as being raped, committing infidelity, or being homosexual, remain punishable by death.

In some cases in the United States and other countries, researchers may consider notifying police of an ongoing research project. This is a difficult decision requiring evaluation of benefits with potential risks. As an example, researchers have interviewed mobile commercial street workers (i.e., prostitutes) about how they negotiate condom use. One potential risk to these researchers is that, if a raid or "sweep" occurs, the researchers and/or participants may be detained or arrested. Some researchers send pairs of staff and/or women to interview female prostitutes (or male prostitutes) because they are less likely to be perceived as "johns." In these cases, researchers should carry copies of research documentation (e.g., IRB approval) and the minimum cash or gift cards possible. Some researchers do choose to identify the research project to local police units. This decision, however, must be balanced against the potential to generate distrust with participants and potentially put participants at risk for identification (e.g., recordings could be seized). If a participant was arrested during or right after an interview, beyond the impact for the participants, a sense of distrust will spread quickly and endanger the project. Some of these concerns about legal status are also relevant for studying illegal behaviors.

Illegal Behaviors

Beyond legal status, researchers may be interested in specific populations engaged in illegal behavior. This is a related but separate question from the participant's legal status, and, in many cases, the two are completely unrelated. Additionally, some definitions of "illegal behavior" are fluid. For example, the behavior of anal intercourse has been selectively prosecuted in the southeastern United States for MSM but not for heterosexual couples. For other behaviors, and research, however, the distinctions are clearer. We earlier described examples of trading sex for crack (Elwood & Greene, 2003), and drug use is an example more generally. The specific case of marijuana in the United States (not just medical marijuana) is an emerging challenge, because as of January 2014 several state laws allowing marijuana sales contradict federal legislation.

Consider the research on needle exchange programs, a successful public health approach to reducing the spread of STIs including HIV (see MacNeil & Pauly, 2011; Strike, Myers, & Millson, 2004). Despite tremendous, documented program success in decreasing transmission of HIV, program funding remains politically contested. Participation in these exchange programs identifies the person as using injection drugs. In one case for our team, law enforcement officers followed a needle exchange worker over a period of several weeks. Police have arrested needle exchange workers in states where this public health practice is illegal. These challenges put participants at risk—and, potentially, the researcher(s) as well.

One understudied area that may receive increased attention is injection drug use, including performance-enhancing drugs or steroids (and potential for disease transmission, beyond other effects). This practice has increased among athletes at many levels and receives some very public scrutiny (e.g., the Major League Baseball controversy surrounding the record for home runs in a baseball season, or Lance Armstrong's doping scandal in cycling). Many of these athletes would reject labeling as "injection drug users," and access to these drugs is often illegal and vigorously hidden from reviewing committees such as the NCAA or Olympics.

Recommendations for research with illegal behaviors are similar to those for legal status mentioned above. Additionally, researchers should consider using "fake names," and, in instructions, ensure that participants do not share certain behaviors, such as robbing a store for drug money or plans to kill a drug supplier to take a stash. If any questionable statements are recorded, researchers should stop taping immediately, rewind the recorder, and record over the statement (and later notify the relevant reviewing body). Researchers could also consider asking participants to "share what others you know do," rather than reporting their own behavior. Any tapes should be transcribed quickly, de-identified, and destroyed. Researchers should also seek expert input on electronic file storage (encryption is one option, but password protection and limited copies also increase protection).

Final Comments

Health research with stigmatized populations presents a unique set of methodological challenges. Lest we forget, some of these populations have very negative perceptions of research and researchers generally. Tuskegee, for example, was active as a research project in the United States into the 1970s, yet many people consider it "ancient history." For some African Americans, however, the distrust remains. Other communities may have similar reticence and question the research or researcher goals. Thus, researchers must be especially vigilant in establishing rapport with communities who may have heightened reactions to potential stigma. This process of establishing relationships, however, can be painstakingly slow. Researchers should observe the group, behavior, or community to the extent possible before embarking on a research project. This requires time and careful planning. Some researchers choose to volunteer for a long period of time before seeking access to participants, and that is one approach. Other teams might hire staff that better blend with the population based on age, gender, race, sexual orientation, or language fluency.

Relationships with both staff and clients can be crucial to successfully complete research projects. Staff may serve as access points, and this can be complicated if there are competing goals. We conducted one study with an ASO in a large city, and one staff member was so motivated for participants to "get the incentive" that she consistently misrepresented inclusion criteria to our staff, even after repeated clarification. Although this action may have been beneficial for participants, it created chaos for the project.

Researchers should also consider what they are giving back to the particular community prior to study onset or recruiting. Besides payment for participation, what would be productive for the group? We provide training sessions for staff, such as with ASOs, yet these approaches only indirectly assist the target population (i.e., clients). To more directly affect communities, researchers working with economically distressed populations could provide a training session on job interviewing or writing a resume. Researchers should reflect on—and may be asked by human subject review committees—what level of incentive is coercive for an economically distressed group?

For some participants, the reason for participating in the study may not be known to others and identification of even participating in the study will concern some participants (e.g., writing the participant a check for payment or signing a list or consent form). Some studies require a "cover story," and we recommend planning a backup story before embarking on research with stigmatized populations. We interviewed a MSM at a local restaurant regarding condom use and risk behaviors, and, when leaving, ran into a friend of his who wanted to know what we were doing. The participant identified the researcher as "a researcher studying African Americans trying to quit smoking." The researcher was able to cover and go along with the story by asking the friend if he was a

smoker and wanted to participate (thankfully not, in this case, or we would have had to report the incident, and likely tell the "friend" that "the study is full").

Focus group methods create unique challenges in research with stigmatized populations: people who hear things may not respect confidentiality. Most focus group protocols directly address this concern in instructions, but participants should be reminded that others might not respect their information (increasingly, this may be included as a warning on a consent form). Researchers should not assume that, because all participants are similar in status (e.g., not in a country legally or hiding their drinking), others will respect their privacy. This circumstance may lead researchers to allow participants to choose other names, similar to what may be done with interviews. In other cases, focus groups are simply not appropriate given the added risk, and individual interviews are more appropriate.

Less seasoned researchers or those accessing a new population should partner with experienced researchers; even a brief consulting meeting could dramatically improve a project. We encourage researchers to thoughtfully consider how their research can decrease—or at least not increase—participants' stigmatizing experiences. Research can be beneficial for participants, sometimes by asking about positive experiences and providing efficacy and skill training at study conclusion to ensure that the research does not contribute to perceptions of stigmatization. Research with stigmatized populations creates unique challenges and opportunities. Successfully navigating these challenges can provide rich data, and also has the potential to decrease some health disparities.

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