

Social Aspects of HIV

Carmen Logie

Working with Excluded Populations in HIV

Hard to Reach or Out of Sight?

 Springer

Social Aspects of HIV

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*For my dearly missed friend and colleague
Xolile Sane “Malume” Mabuza, in memory of
your joyful, fierce, and courageous activism
founding The Rock of Hope in Eswatini and
improving the lives of lesbian, gay, bisexual,
and transgender persons around the world.
Rest in power.*

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Chapter 1

Introduction



What do you think of when you hear the term ‘hard to reach’? Does a glass on the top shelf in the kitchen come to mind, and needing to bring a step stool over to reach up and grab it? Or perhaps as a researcher, do we think of the challenges we face when people don’t show up to our study, and we are left waiting for them? Or maybe we are unable to find the people identified as at ‘risk’ for HIV who are the focus of our research, making it challenging to meet funding deadlines.

Trying to reach persons who do not seem to want to engage in research, or who we find difficult to locate, is a daunting and at times frustrating endeavour. Why don’t people just want to come in and take part in our important study that can potentially benefit them? Is it something about them, maybe their lives are too chaotic? Maybe they do not understand what it is about, and they need more information to make the choice to participate. Or perhaps they have not heard about the study, and we need to figure out how to spread the information to them. Or maybe it is challenging for persons to access the study site due to limited internet or living far away and lacking reliable transportation. All of these scenarios lead us down a path whereby we think that the problem is something that lies outside of ourselves as researchers, and the solution might be to find the metaphorical step stool in order to help people to participate.

But what if instead of looking outside for the problems that create barriers for people to engage with us, we start looking inside ourselves to our own actions and beliefs as researchers? Would we find new perspectives and solutions to thinking about the people researchers find hard to reach? This chapter will provide an overview of the existing literature on people categorized as hard-to-reach and ‘hidden’. Specifically, it explores the historical use of these terms and the ways in which they have been applied in HIV research and practice. Attention is paid to how this vocabulary has been used to frame particular communities discussed throughout this book who are disproportionately impacted by HIV.

1.1 Historical Use of the Concept ‘Hard to Reach’

The concept of people as hard to reach is common in health—particularly HIV—research. For instance, a quick Google Scholar search of the term ‘hard to reach’ in late 2020 resulted in 4,310,000 hits. Since 2019, there were 67,300 hits. This term has undoubtedly entered the scholarly lexicon. Yet it also remains “contested and ambiguous” with no clear or agreed upon definition (Flanagan & Hancock, 2010). There are many definitions of the word ‘hard’. In the Merriam-Webster dictionary, *hard* can be defined as: “difficult to accomplish or resolve: TROUBLESOME”, “difficult to comprehend or explain”, and “having difficulty in doing something”.¹ *Reach* can be defined as “to stretch out”, “to touch or grasp by extending a part of the body (such as a hand) or an object”, “to extend to”, and “encompass, to make an impression on, to communicate with”.² In fact, as we can see with the MacMillan dictionary thesaurus definition of ‘*not near and difficult to reach*’ the term can mean many things, including distant (remote, far from where you are), isolated, inaccessible and “outermost” (positioned far from the centre).³

A literature review reveals the many terms conflated with the notion that persons may be hard to reach, including: vulnerable, marginalized, transient, forgotten, and underserved (Flanagan & Hancock, 2010). Inherent in viewing people as hard to reach is the understanding that they experience social marginalization and stigma that marks them out as different and results in differential access to power and subsequently to resources. Persons marked as hard to reach can also include those who experience challenges accessing health care, such as people with physical, mental, auditory and speech challenges. As a consequence, persons who experience stigma, existing health challenges, and marginalization are often categorized as hard to reach.

Historically, the terms ‘hard-to-reach’ and ‘hidden’ populations were not used to describe sub-populations that may be difficult for researchers to access due to stigma, legal confrontations, and physical or other barriers. Persons were instead identified by a particular and specific identity or experience. For example, people who use drugs and sex workers were not referred to as hard-to-reach nor hidden populations but simply as people who use drugs or sex workers. The term hidden population appears to have first emerged in research and literature around 1974 in the UK, in a paper by Bayley who described the pervasive stigmatizing social norms and discriminatory attitudes from police experienced by lesbian, gay and bisexual persons (referred to as ‘homosexuals’ in the paper) (Bayley, 1974). Bayley coined the term, “hidden homosexuals” to describe people who concealed their sexual orientation from family, friends and especially the police to avoid humiliation, shame and police brutality (Bayley, 1974). In 1976, a paper about the culture and

¹Definition of hard by Merriam-Webster, <https://www.merriam-webster.com/dictionary/hard>.

²Definition of reach by Merriam-Webster, <https://www.merriam-webster.com/dictionary/reach>.

³Synonym of not near and difficult to reach by MacMillan, <https://www.macmillandictionary.com/thesaurus-category/british/not-near-and-difficult-to-reach>.

social structure of “gypsies” in America referred to this group as a hidden population because they were nomadic and researchers struggled to reach this population (Morrison & Morrison, 1976).

The term hard to reach became more widely used in the field of social marketing when it was applied to health initiatives for behaviour change (Beder, 1980). Social marketing strategies highlighted the need for creativity and additional funding to reach persons not typically included in standard campaigns. Thus, while in the past people were identified due to socio-demographic characteristics, health and/or social practices, there was a move that appeared to begin in the 1970s to describe persons with the terms hidden and hard to reach. Fast forward to the present day, where there are countless thousands of articles using these terms.

1.1.1 Who Do We Call Hard to Reach?

Hard-to-reach audiences have been called obstinate, recalcitrant, chronically uninformed, disadvantaged, have-not, illiterate, malfunctional, and information poor. These labels reflect communicators' frustration in trying to reach people unlike themselves and the failure of many campaigns to change high-risk behaviors (Freimuth & Mettger, 1990, p. 323).

The term hard to reach is ambiguous and not well defined and, as described in the above quotation, can reflect our own frustrations of not being able to engage with persons that are in some ways different than ourselves. When researchers and service providers find a population difficult to access for any number of reasons, that population may be labelled as hard to reach. There are numerous ways in which hard to reach persons have been conceptualized. Tourangeau (2014) has disentangled some of the different ways in which people may be experienced as hard to reach: differentiating between hard to sample, hard to identify, hard to find or contact, hard to persuade to participate, and hard to interview. Doherty, Scott, and Kinder (2004) described three hard to reach categories with regards to service delivery: under-represented, including marginalized and socially excluded persons such as ethno-racial minorities and refugees; 'slipping through the net', persons who are invisible, overlooked and/or have constrained agency to voice their priorities, including persons with mental health concerns; and persons who are 'resistant' to services, for multiple reasons, including mistrust, persons targeted by police, and persons who are otherwise disinterested. There are therefore myriad ways that the term hard to reach is applied to understand disengagement and lack of inclusion. Other approaches are detailed below and include (a) sociodemographic, disengagement, and logistic dimensions; (b) dimensions and corresponding tools to identify and work with hard to reach persons; (c) and hidden populations, including persons who do not want to be reached.

1.1.2 Dimensions of Hard to Reach

People may be labelled hard to reach when they share particular socio-demographic characteristics, are disengaged from research and/or health and social services, and when they experience logistic barriers to participation. First, the term hard to reach has been applied across social group memberships. For instance, the label has been applied to: women; lesbian, gay, bisexual, transgender and other sexually and gender diverse persons; ethno-racial minorities; people experiencing homelessness; people who use drugs; sex workers; youth; the elderly; migrants and refugees; people living with HIV; and highly mobile persons (Bacher, Lemcke, Quatember, & Schmich, 2019; Ellard-Gray, Jeffrey, Choubak, & Crann, 2015; Flanagan & Hancock, 2010). A systematic review of 116 studies identified the most commonly referred to hard to reach groups as ethnoracial minorities (40 studies), African American people (19 studies), people who use substances (14 studies), and others more generally labeled vulnerable, minority, or disadvantaged ($n = 11$) (Bonevski et al., 2014). This long list of identities and practices reveal that people belonging to many different sections of society may be labelled hard to reach (e.g., women at large) as well as smaller populations (e.g., sex workers)—revealing the term’s lack of specificity. These lists of identities and practices also overlook the intersectionality between social practices and identities, and the implication of holding multiple marginalized identities or practices on being categorized as hard to reach. For instance, is a sex worker who uses drugs easier or harder to reach than non-sex workers who use drugs or sex workers who do not use drugs?

Hard to reach has also been applied to characterize persons who are underserved by social and health services. People’s individual attitudes are often considered relevant to disengagement from services. For instance, Brackertz (2007) has described how persons may feel that they are not heard, cared for or about, and/or that services are irrelevant, and therefore may actively decide to disengage. In turn this decision could result in their categorization as hard to reach. Flanagan and Hancock (2010) have thoughtfully discussed the ways that people who do not use services are labelled as hard to reach. Low service uptake could be for many reasons, including persons using non-traditional approaches and resources and in turn not wanting or needing particular services. Although persons who experience greater financial or class privilege may choose not to utilize particular health and social services, or to take part in a research study, they are rarely given the hard to reach label. This suggests that hard to reach is uniquely applied to more marginalized communities and identities experiencing poverty or less class privilege. In this way, hard to reach has become a stigmatizing phrase. Researchers’ focus on marginalized populations categorized as hard to reach also reflects a general lack of attention toward persons that are not hard to reach, and who in fact are able and willing to access and participate in research (Katz, Hardy, Firestone, Lofters, & Morton-Ninomiya, 2020). In this way less attention is paid to privilege and power and the ways in which research studies can reproduce existing systems that benefit certain groups while excluding others.

Research studies may not be designed to meet the priorities of the focus population, who in turn make the decision to not participate in research that is not directly relevant or perceived as beneficial. For instance, to avoid duplication of services and to build on existing resources and expertise, agencies may focus on providing a specific service rather than a menu of services (e.g., offering HIV testing alone instead of offering other sexually transmitted infections testing and contraception). This can result in socio-economically and/or geographically marginalized people having to choose where to invest their time or money. Services that are funded may not in fact reflect the priorities of the hard to reach. For instance, a focus of HIV research on LGBTQ communities may look at persons characterized as at high risk for HIV rather than the larger LGBTQ community (Logie & Gibson, 2013). This HIV focus may mean that researchers want to engage LGBTQ persons—but in actuality only include gay and bisexual men and trans women—in HIV prevention and care research. Such an approach actively excludes lesbian, bisexual and queer women from access to community resources, solidarity and social support systems while reinforcing heteronormative beliefs regarding sexual identities and practices among lesbian, bisexual and queer women. Sexually diverse women have unique HIV prevention needs based on sex work engagement, multiple partners, and/or injection drug use, to name a few (Logie, 2015), but these then get ignored. At the same time, an emphasis on HIV biomedical prevention for LGBTQ communities globally can overlook the larger social determinants of health that create elevated exposure to HIV, including family and social exclusion and related mental health challenges, employment discrimination, education discrimination, and housing discrimination. While these larger issues may reflect the priorities of LGBTQ communities, they may often remain beyond the scope of HIV funding envelopes.

Finally, the hard to reach label has been applied to persons who experience logistic barriers to participation. To illustrate this, persons may be classified as hard-to-reach due to their physical/geographic or social locations, including living in remote geographical locations or social elites (Ellard-Gray et al., 2015; Shaghghi, Bhopal, & Sheikh, 2011). Accessibility barriers may produce hard to reach experiences. Services may be physically inaccessible, via socio-economic concerns such as transport, the lack of childcare, narrow hours, and limited flexibility in one's employment. Other physical access issues include venues that are not wheelchair accessible, or services otherwise not tailored to meet the needs of persons with a disability. Finally, logistic barriers can include a lack of culturally and linguistically relevant resources to facilitate participation. Simply listing these diverse groups of people as hard to reach can overlook the way that positionality is contextually produced, meaning that where people are socially and economically located and how open they are to participating in a service or research project can shift over time and place and reflects larger social and structural inequities.

Social geographies produce particular risks. For instance, research has documented social and health disparities based on public place of sex work (Logie et al., 2020; Logie, White, Galai, Tomko, & Sherman, 2020). Sex workers who work in public settings in contexts where sex work is criminalized experience heightened criminalization and may have to work with a sense of urgency to avoid police arrest,