Social Science & Medicine 211 (2018) 175–182

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

“There was no love there”: Intergenerational HIV disclosure, and late presentation for antiretroviral therapy in Northern Malawi

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ARTICLE INFO

Keywords:
Malawi
Children
HIV disclosure
Late presentation
ART
Grandparents
Ethnography
Stigma

ABSTRACT

Despite access to antiretroviral testing and treatment, high rates of mortality among HIV infected infants and young children persist, often because they are diagnosed too late to benefit from treatment. Most research assumes that treatment delays are a proxy indicator for ongoing HIV-related stigma. My argument is different. Instead I argue that secrecy and truth-telling are socially produced; that is I consider how gendered and intergenerational dynamics regulate how and to whom secrets should be shared. In this article I draw on two years of ethnographic fieldwork (2008–2010) in Northern Malawi with 35 HIV positive children, their primary caregivers, as well as multiple interviews with their extended therapy networks [N = 96] and community stakeholders [N = 72] to examine how social hierarchies influenced the timing of an HIV diagnosis for infected infants. My findings indicate that it is neither necessary nor strategically advantageous for some women to disclose their HIV status to their husbands. Rather, grandparents play pivotal roles at facilitating HIV disclosure between intimate partners, which in turn leads to timely HIV diagnoses for infected children. This article contributes to a body of literature that questions the usefulness of the concept of “stigma” for understanding late presentation for ART among infants and children.

1. Introduction

The routinization of HIV testing during pregnancy is widely envisioned as the primary gateway to HIV prevention, care and treatment services for both adults and children (Angotti, 2010; UNAIDS, 2013; WHO, 2010). Although routine testing has significantly increased the number of pregnant women being tested for HIV, (successfully preventing thousands of new pediatric infections every year), the effects of the strategy on antiretroviral therapy (ART) uptake are underwhelming (Abrams et al., 2017; Kalua et al., 2017). Despite concerted global efforts, treatment rates for infant and children rates remain far below global targets. Globally, the median age at time of diagnosis for children is 3.8 years; this is a serious problem given that most children with HIV die before the age of two without timely access to ART (UNICEF, 2016). Most research assumes that treatment delays are a proxy indicator for ongoing HIV-related stigma. My argument is different. Instead I argue that secrecy and truth-telling are socially produced; that is, I analyse the broader social context of HIV disclosure within multigenerational households and consider the concomitant impact on the timing of ART uptake for infants and children infected with HIV in Malawi.

In particular, I analyse how HIV disclosure practices are being reshaped by “One Love”, an ongoing public health campaign aimed at encouraging companionate ideals of transparency and emotional intimacy within a single monogamous relationship (married or not). A key message of this campaign is that intimate partners should know and disclose their HIV status to each other (UNAIDS/Soul City Institute, 2008). From a pubic health perspective HIV disclosure is characterised as a prosocial behavior that facilitates timely ART initiation and lifelong treatment adherence (Grossman and Stangl, 2013; Tsai et al., 2013). Thus, the premise behind efforts to “break the silence” around HIV/AIDS, is that disclosure will ultimately reduce HIV-related stigma, decrease HIV transmission rates and increase HIV treatment uptake for both adults and children (Hardon and Posel, 2012: 1; Esacove, 2016). However, my findings show that the men and women who are the targets of this initiative contest and renegotiate new marital expectations that emerge from these efforts. Significantly, most households in Malawi are multigenerational, and grandparents are also interpreting these messages in their own ways. Grandparents, who are not the targets of this initiative, reassert their authority to intervene in marital relationships and child care decision making by drawing on their authority to *tell* secrets. Thus, I show how social hierarchies within multigenerational households shape disclosure practices between intimate partners and that understanding these dynamics is critical to understanding delayed ART uptake for both adults and children.

My findings indicate that women in long term stable relationships

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https://doi.org/10.1016/j.socscimed.2018.06.025
Received 20 December 2017; Received in revised form 21 June 2018; Accepted 22 June 2018

with shared children, either disclosed their status “straight out the same day” or asked their husbands to go for an HIV test together so that the secret could be revealed by a health care worker – a strategy that was encouraged by the hospital (see also Anglewicz and Chintsanya, 2011; Lugalla et al., 2012). Yet, the presence of a father in a child's therapy network resulted in significant treatment delays, and, in at least two cases that I know of firsthand, their untimely deaths from HIV-related symptoms. One two year old boy died two weeks after he started treatment, but months after he developed serious HIV-related symptoms. It turned out that both parents knew their HIV status the whole time, but never discussed their status with each other, which ultimately contributed to his early death. In this article, I use ethnographic data to explain how this happens and what it means for service providers trying to facilitate timely treatment initiation.

A significant finding from my research that has not been discussed in the literature indicates that HIV disclosure processes that result in timely ART uptake often involve alternate generations, or “the grandparents”. In Malawi the concept of “Grandparents” is classificatory and used broadly in everyday life to refer to social interactions between alternate generations. When the caregivers I talked to referred to “the grandparents” they were often talking about their parents'-parents' generation in a very broad sense. As Radcliffe-Brown (1940) found decades ago, communication norms between different generations, such as a grandparent and a grandchild are defined as “joking”, or characterised by openness and informality, whereas communications norms between a child and a parent or between spouses are more formal (see also Kyanddondo et al., 2013; Lwanda, 2003; Mandalazi et al., 2014; Vale et al., 2017). Grandparents in Radcliffe-Brown's analysis also had the authority to intercede in the relationships between parents and their children (see also Fortes, 1949: 236–240). More recent research on the fostering of AIDS orphans by grandparents throughout Africa support these earlier observations. For example, studies highlight how children raised by grandparents are often considered spoiled and undisciplined, since grandparents are more like friends to their grandchildren than disciplinarians (Abebe, 2012; Young and Ansell, 2003). What is critical here is that the familiar or “joking” quality of the grandparent-grandchild relationship facilitates truth-telling around HIV/AIDS.

My findings illustrate how “Grandparents” (usually older female relatives) were often able to successfully mediate HIV disclosure between intimate partners by advising one or both of them to go for an HIV test; they were also the driving force behind most HIV diagnoses for infected children. This intergenerational HIV disclosure process reflects an established truth that elders are wise and able to guide others, as well as the continued relevance of generational authority in Malawi (see also Bezner Kerr et al., 2008). While some argue that the importance of grandparents is being undermined by widespread social change, which makes their experience and knowledge seem irrelevant (see for example Van der Geest, 2004), my findings suggest the opposite. Rather, grandparents are reasserting their role as trusted advisors and confidantes and inserting themselves into the disclosure process to secure an HIV diagnosis for infected children, often without their parents' consent.

These findings highlight the conceptual inadequacy of “stigma” for understanding late presentation for ART. The concept of “stigma” is too often poorly defined and rarely adequately addresses the multi-dimensional dynamics of HIV disclosure processes (see also Dima et al., 2014). For example, it cannot explain why some women easily disclose their HIV status to their husbands, while some face adverse social and economic consequences (Obermeyer et al., 2013). Nor does the concept account for the many ways that people in Malawi discuss HIV with each other (see Kaler and Watkins, 2010; Schatz, 2005; Watkins, 2004). Thus, my conclusions help us understand why pushing pregnant women to disclose their HIV status to their husband's first or emphasising male-partner involvement in HIV prevention programs are unlikely to facilitate timely ART uptake for many children.

These complex social dynamics raise a number of relevant questions for health providers trying to increase treatment uptake for both adults and children. However, prior to discussing the policy implications I will provide some background on the research methodology and clarify the theoretical framework for this project. To analyse HIV disclosure practices within multigenerational households I draw on anthropological questions about the purpose of secrecy in Africa. After setting up the theoretical framework I return to the main analysis of HIV disclosure practices within multigenerational households. First, I focus on “One Love” as a public health intervention trying to facilitate HIV disclosure between intimate partners. Second, I analyse the impact of these efforts on intimate relationships and finally I discuss the role grandparents play at securing ART for infected children. I conclude with specific policy recommendations for service providers.

2. Methodology

The data presented in this article are part of a larger project on barriers to ART uptake for infants and children in Malawi, which involved twenty months of fieldwork in Northern Malawi (April 2009–December 2010). This research was conducted in collaboration with a government run rural hospital in a town I call “Temwa” (all names and places have been changed). I was referred to Temwa by the Ministry of Health since tertiary health care settings represent the standard of care for the vast majority of Malawians, where 83% of the population resides (NSO, 2017). During my research the ART clinic was run by a small team of professional and community health care workers and provided free adult-dose split-tablet regimens of ART to children as part of a global effort to provide HIV care for infants and children for the first time (MOH, 2008).

For this study, I employed a number of methods to obtain data (INSERT LINK TO ONLINE FILE A). First with the help of the ART clinic staff I recruited thirty-five children (0–14 years old) the day they were diagnosed with HIV for in-depth semi-structured interviews and repeat home visits (mean age on the day of diagnosis = 3 years). In total, 35 children living in 32 households (19 boys, 14 girls) with HIV were recruited. All of their primary caregivers (mostly mothers) and extended therapy networks (mostly grandparents) (N = 96) were interviewed at least once but up to ten times. At the end of my research in 2010 this represented all but two of the children on treatment at this hospital. Topics discussed included: stigma experienced by HIV positive children and their caregivers, the symptoms first noticed by specific family members, the steps they took to deal with the illness, who they consulted, and experiences with HIV diagnosis and disclosure. Other stakeholders (N = 72) were also purposively sampled to represent a range of perspectives on infant HIV diagnosis and included health officials, traditional healers, policy makers, service providers, grandparents with knowledge about child health, religious leaders and health care professionals. A limitation of my study is that so few fathers were alive and involved as primary caregivers (only 5 of the 32 households included a biological father). To mitigate this issue I purposively sampled a range of men from different socioeconomic backgrounds (N = 26) for in-depth interviews on health care decision making and HIV disclosure within households. A focused ethnographic survey on health strategies for sick children (N = 496) helped triangulate my findings. For example, a key finding from this survey is that when asked: “Who did you consult first about the child's symptoms?” a grandparent was always consulted prior to visiting a hospital (Sikstrom, 2015). The second major source of data comes from 20 months of participant observation at Temwa Rural Hospital. At least twice a week I spent a full day at the hospital observing pediatric HIV treatment “entry-points” identified in Malawi's national HIV treatment guidelines, such as the Prevention of Mother-to-Child Treatment (PMTCT) program, the ART clinic, the outpatient department, mobile clinics and the maternal and child health clinics. Finally, on a more informal level, I relied on the anthropological method of participant observation to further contextualize health care