

Jean Burke, School of Social Work, Australian Catholic University Swahili-based concepts: Explaining how social ties manage HIV and infant feeding

Abstract

In Tanzania where HIV transmission is high, decisions to avoid or modify breastfeeding are crucial for infant survival yet difficult due to competing risks. A study in Central Tanzania explored the role of social dynamics in infant feeding decisions to prevent HIV. Qualitative data was collected from in-depth interviews and focus group discussions with people living with HIV and community members, including village leaders, traditional healers and midwives within the Dodoma region. Data was analysed using grounded theory and natural Swahili language.

Emerging themes were based on Swahili categorisations. In the context of HIV, infant feeding is a moral issue of fear and safety (*salama*); decisions seek to maximise *kinga* (immunity). Swahili-based conceptualisations were used to explain how social relations (*jamii*) manage HIV and infant feeding in complex, dynamic ways, by acting as *kinga*, and as gates of open paths for the flow of capacities (*uwezo*) into and within networks. The use of language in this study opened up Tanzanian ways of thinking, some of which are positive dimensions to more widely embraced negative concepts, especially ideas of maximising immunity (rather than reducing risk), building openness (rather than fighting stigma) and embracing responsibilities (rather than demanding rights).

Key words: HIV, Infant feeding, Social relations, Immunity, Swahili language

Introduction

Culture and language are important resources which people bring to development and to responding to HIV. In a qualitative study conducted in Central Tanzania certain Swahili concepts emerged as important for how social ties manage infant-feeding decisions to prevent HIV. Data analysis was guided by the grounded theory principle of using natural language including developing categories of Swahili concepts used by respondents themselves. Hence the themes in the findings were based on Swahili categorisations to explain how social ties manage HIV and infant feeding in complex and dynamic ways.

The issue: infant feeding and prevention of HIV

HIV in Africa is a 'family burden' (Kaleeba cited in Ankrah 1993, p5), which is a challenge for the African family to manage and prevent. In the United Republic of Tanzania, preventing infant HIV is a prominent issue in infant health. Without intervention, about one-third of children born to mothers with HIV will also be infected, and one third to one half of these will be infected through breastfeeding (De Cock et al. 2000). Since the majority of children are breastfed in Tanzania (94%) (National Bureau of Statistics [Tanzania] (NBS) 2005, p177) a critical dilemma is that while HIV may be transmitted during breastfeeding, avoidance of breastfeeding may contribute to infant malnutrition, illness and deaths. Furthermore, mothers who feed their

infants contrary to community expectations and practice may be exposed to social risks, such as stigma, social pressure and rejection by male partners and other kin.

International and national guidelines keep shifting in response to evolving evidence, including the increased HIV risk of mixed feeding (i.e. feeding with breast milk in addition to other liquids and solids) (World Health Organization [WHO] 1981, 2001) as more risky than exclusive breastfeeding (i.e. breastfeeding while giving no other food or drink, with the exception of drops or syrups consisting of vitamins, mineral supplements or medicine) (WHO 1981, 2001). The policy at the time of this study promoted replacement feeding as the first choice with exclusive breastfeeding only when replacement feeding was not affordable, feasible, acceptable, safe, and sustainable (known as AFASS conditions). This policy version has predominantly influenced programmes to prevent infant HIV throughout sub-Saharan Africa over the last decade (Moland et al. 2010). Diverse studies demonstrate how these guidelines tend to be out of touch with people's lives and local conditions and with local knowledge of breastfeeding as a cultural practice (Blystad et al. 2010).

Current guidelines show growing recognition of the importance of social and cultural context and local knowledge. The 2010 policy recommends exclusive breastfeeding for the first six months as the method of choice, with complementary feeding after six months as well as gradual weaning and replacement feeding only when specific conditions are met (WHO, Joint United Nations Programme on HIV/AIDS [UNAIDS], United Nations Children's Fund [UNICEF] and United Nations Population Fund [UNFP] 2010), which is close to general public health recommendations. Whatever the policy context, deeper understanding about the social interpersonal context of infant feeding in relation to HIV can assist planning and implementation of prevention programmes and community education, such as formulating messages grounded in people's concerns and experiences. This study aims to expand understanding of the context of decisions to prevent infant HIV (de Paoli 2004) and explore ways to encourage supportive partner, family and community involvement (World Alliance for Breastfeeding Action [WABA]/ UNICEF 2002, p71).

The study

The study on which this paper is based was conducted in Dodoma Urban District and several rural villages in the Dodoma region of Tanzania. The predominant tribe is Gogo who are semi-pastoral. Swahili is the official national language of Tanzania and the medium of instruction in primary schools and adult education. Swahili belongs to no one ethnic group: it has been used intentionally to break down tribal boundaries and build nationalism. However the mother tongue of most people is their tribal language, such as Kigogo (spoken by the Gogo tribe).

The research study discussed here aimed to explore the perception and attitudes to HIV and infant feeding among community members and their perceived and potential role in supporting prevention of HIV transmission. A sample of six HIV-positive mothers from a self-help group of people living with HIV and four relatives of mothers with HIV were interviewed in-depth to provide understanding about HIV and infant feeding and relevant support from their own experiences. A larger sample of twenty key informants, including health workers, policy

developers and opinion leaders were also interviewed. Focus groups were selected purposively mainly according to the criteria of gender, age, life stage and location. This led to focused discussions with urban groups of Muslim women and people living with HIV and rural groups of younger and older grandfathers and grandmothers, mothers and fathers as well as village leaders, traditional midwives and healers.

Three languages were used in the data collection process: English, Swahili and Kigogo. Key informants chose to use English or Swahili, while relatives and mothers with HIV used Swahili. Most group discussions were conducted in Swahili but some also used Kigogo, with the assistance of an interpreter. Transcriptions of the audio-taped data were analysed thematically, using grounded theory developed by Glaser and Strauss (1967), which encourages the use of natural language and 'in-vivo coding' (Strauss & Corbin 1990) from language used by informants. The data was analysed with minimal translation to English, both to save time and retain meaning, a strategy advocated by Strauss and Corbin (1998) for these reasons. My own fluency with Swahili made this possible. Analysis developed categories of Swahili concepts as core organising themes for building a framework to understand how social ties influence infant-feeding decisions. The idea of using concepts as culturally available resources, as posed by Jordens (2006) reinforces their value in building explanations in complex contexts. Their use in this study acknowledges that cultural and linguistic conceptualisations provide entries to understanding and responding to HIV, and are not just barriers to health promotion.

The themes: Swahili-based concepts

The use of language in this study opened up Tanzanian ways of thinking, some of which are positive dimensions to more widely embraced negative concepts, especially ideas of maximising immunity (rather than reducing risk) and building openness (rather than fighting stigma). The following concepts and themes have been selected from the many findings as the more useful for understanding and application in the East African context of HIV.

Salama

Survival of children was prioritised by study respondents when evaluating what form of infant feeding was best. Divergent arguments of diverse methods were based on experiences of children exposed to HIV who were 'going well', who were alive and healthy whether they were presumed or tested HIV-negative or even had HIV. For example, one mother with HIV, narrated several stories of babies born to HIV-infected mothers, who either wet-nursed, or used goat's milk or hospital-provided formula milk. She reported on the results, respectively: '*She grew well and is walking now*'... '*He is going well*'... '*Now the child is big... and going well at school*'. This is primarily a reference to their external health, rather than HIV status since she also reported that an HIV-infected mother is 'going well'. The word *salama* was prominent in these discussions as the sought-after goal or achievement. This concept means safety, sound health and peace. Depending on the context, *salama* can mean well-being (regardless of a person's HIV status), or being HIV-free¹. In this way HIV status is understood holistically, rather than in terms of laboratory blood results.

¹ *Salama* has been appropriated for commercial use as a brand name for condoms.

For some respondents, choices about infant feeding in the context of HIV were a moral issue of fear and *salama*. Milk was described in binary form, morally judged as safe or dangerous, good or bad. Breast milk, instead of signifying life and health, was perceived as bringing death and danger. Fear was more commonly spoken about than risk, which is more common in Western discussions. No single word in Swahili represents 'risk' as uncertain danger, instead, separate words are used, either danger (*hatari*) or uncertainty (*mashaka*). At the other conceptual end, however, *salama* covers both safety and security. Notions of risk as a cultural construction (Zinn 2006) suggest that uncertainty may be feared and risk understood as certain danger rather than in a more nuanced way. So local perceptions of risk attach danger to breast milk itself, and then prescribe a response of risk elimination, such as weaning, rather than managing risk.

Maximising *kinga* (immunity) was an important way that people evaluated methods of feeding infants. In Swahili, *kinga* means immunity, antibodies, protection or more literally, shield². *Kinga* is a central idea to HIV and AIDS and is a key word in *UKIMWI* (*ukosefu wa kinga mwilini*), meaning AIDS. Study participants referred to this concept when evaluating breast milk and other kinds of milk in relation to HIV infection and child survival. They discussed the *kinga* of breast milk, being the maternal antibodies that give infants protection from all sorts of diseases and the *kinga* of cow milk, which was free of HIV. A few stated metaphorically that replacement milk was itself *kinga*, or protection, in contrast to the 'poison' of breast milk. Hence, breast milk and replacement milk have different kinds of *kinga*: maternal antibodies or being HIV-free. This positions *kinga*, or immunity, as an asset situated in mother's bodies or accessed as a resource in the community. Respondents also spoke about people having varying levels of *kinga* to explain variations in people's health or (lack of) infection.

Respondents noted how poverty affects maternal nutrition and hence decreases immunity and how wealth can purchase *kinga* in the form of medicines, including antiretrovirals, and replacement milk. The attention of respondents, however, was clearly on ways to boost or maximise the immunity available, through nutrition, or the purchase or supply of medicines. So, for example, the idea of mothers using antiretroviral drugs while breastfeeding was generally approved of, as a way to combine both kinds of immunity, rather than trading them off, and as a way to support the well being (*salama*) and survival of both mother and child. Moreover, respondents exemplified how social ties could be channels for providing *kinga* (immunity) in order to save children's lives. One village leader linked such collective responsibility to preventative action: '*Because it is the community of the child...some good people will give out help if they can give it...protection (kinga) so the child won't get it.*' By providing cow or other milk, such people in the community would be seen as giving protection to the child from HIV transmission.

Uwezo

Uwezo was an important Swahili concept referred to by respondents when discussing the comparative options of infant feeding methods and the involvement and influence of others.

² Within sexual relations *kinga* is a term used for condoms.

The word *uwezo* means ability, power and authority. As a broad flexible term *uwezo* refers to any available resources or powers, which can enable action, encompassing material wealth, abilities and social resources. Hence, distinctions in socio-economic status are often signified and discussed in terms of differing amounts of *uwezo*, or its presence or absence. For example one health worker described how *'the capacity (uwezo) in the villages is small. For cattle owners it is easy... the mother can...keep giving cow's milk without anxiety... But for small farmers who don't have capacity (uwezo), who depend on the hand-hoe, it will be difficult.'*

Respondents considered different types of *uwezo* as relevant depending on the kinds of infant feeding choices. The capacity to choose or not was a kind of moral *uwezo* which some respondents spoke of as a kind of 'non-choice'. This could mean that breastfeeding may be seen as morally unavailable due to potential HIV infection, or physically unavailable due to maternal illness, with consequent struggles to obtain available milk. Or breastfeeding may be seen as the only option due to lack of economic resources (*uwezo*) to afford replacement milk. Respondents focused more on issues of physical *uwezo* when discussing breastfeeding, while issues of economic *uwezo* were considered more relevant for replacement milk decisions. Physical capacities, such as *kinga*, maternal and breast health and milk production were relevant to assessing and encouraging safer forms of breastfeeding, such as exclusive breastfeeding or heat-treating breast milk. But economic resources can influence these capacities, by ensuring access to medicines, sufficient, nutritious food and rest. The issues related to replacement milk spoken about by respondents were availability, cost and knowledge about how to prepare them. Access to milk is a match between individual capacity to afford it and availability in the community.

The way *uwezo* is used indicates it is understood as power or capital which is dynamic, social and interactive power in a way that is less usual in English. Other Tanzanian studies have also noted the dynamic, diverse and relative nature of this concept (Gregersen 2003; Myers 1996). This means influence is seen to exist and flow through social relationships in order to access resources, such as milk and medicines that can be used to prevent HIV transmission. Hence while a mother may seem to have no capacity to afford milk, negotiating through social connections may yield milk to act as protection, through what works as a "moral economy of interdependence" (Robertson 1998, p1428). This informal economy through social connections operates in complex ways, using leverage through gender and generation hierarchies, that is, fathers and elder kin. *Uwezo* was a frequently recurring concept in any discussion about access. Strategies for access included household-sharing, gifts, loans, group meetings and collections, petitions and delegations, sometimes in complex mixes of social and economic transactions with milk accessed as a commodity, gift and/or service. Respondents noted that the possibility of family involvement should be acknowledged and addressed by health services.

Aibu

The concept of *aibu* (or shame) emerged as an important social force that restrains speech and actions. Shame affects infant feeding choice: mothers wishing to avoid shame (of maternal irresponsibility or suspicion of HIV infection) might choose to breastfeed in the conventional way, rather than use replacement milk or breastfeed exclusively, particularly first-time

mothers. Such shame comes from comparisons to peer values, such as not breastfeeding signaling HIV infection or failed motherhood (Moland 2004). According to this study, the power of shame (*aibu*) to influence actions was more powerful for young mothers, especially those having their first child.

Amongst study respondents fear and shame took a more prominent place than stigma as driving forces restraining choices. Only health workers and people living with HIV discussed stigma, as *unyanyapaa*, which also means harassment. Stigma is a new concept within Swahili, derived from Western education rather than African experience, but adopted as useful by those who experience its effects and by Tanzanian experts. Research in Tanzania by Kilonzo et al (2002) also noted this challenge and concluded programmes will need to explore how to indirectly talk about stigma. 'Stigma' loses some of the nuances in how most people in this study in Central Tanzania talked primarily about its effects: blame, shame, fear, rejection, withdrawal, despair and so on. This runs counter to tendencies in Western and international discussions to focus on reducing and 'fighting' stigma, a negative term without an obvious contrasting positive one. It is noteworthy that respondents spoke more about accepting HIV, being open and focusing on solutions such as building an environment in which stigma does not thrive, to widen choices for infant feeding and protect mothers' dignity.

Uwazi

Confidentiality (*siri*) is valuable in the context of HIV because secrecy respects an individual's rights and functions to protect specific women from the possibility of misunderstanding, shame and isolation. Yet people in this study talked about how fear and secrecy (*siri*) foster the spread of HIV, and advocated openness (*uwazi*) as an important way to stop HIV spreading. The positive concept of *uwazi* was talked about in many ways, most commonly used figuratively to mean transparency and clarity, in the sense of free unimpeded access through an opening (*uwazi*), such as free flow of information without hindrance. Within social relationships, openness (*uwazi*) is a state of open honesty and communication, acceptance and understanding which contrasts with hiding and keeping secrets (*siri*).

Openness (*uwazi*) is an ideal which respondents recommended individuals, leaders, groups and institutions embrace in order to prevent infant HIV. Central aspects to such openness are ideas of honesty and reality in relation both to communication and knowledge, that is, open discussion about HIV and honest disclosure of HIV status details, such as being tested. Usually HIV is not openly discussed in East Africa. Even though such open communication is a new way of interacting, research participants talked about this as important change that had started and needed to occur in their society in order to respond to HIV effectively. Then people can learn different ways to talk and act within these collective built open social spaces. Openness at some level was seen as necessary for effective support of mothers to occur, and for sharing responsibility for preventing infant HIV rather than being borne solely by the mother.

Openness makes mothers' contexts more conducive for infant-feeding choices to prevent HIV. Because it changes risk environments to supportive ones that block HIV flow, it is a form of *kinga*. A village leader aptly expressed this idea, that openness provides immunity against

infant HIV: 'People should recognise this matter, if it was open (*wazi*) then they would have a certain protection (*kinga*) by understanding this is a problem.' Openness and the infant-feeding practices it permits can act as a 'social vaccine' (Green 2003, p222), just as openness and changes in sexual practices in Uganda had a reductive effect on HIV transmission similar to a physical vaccine (Hogle et al. 2002; Stoneburner & Low-Beer 2004). Crucial aspects to the openness identified in the successful Ugandan response included open communication by leaders and through citizens actively sharing information within open personal networks (Hogle et al. 2002; Low-Beer et al. 2000) and mobilisation of civil society, particularly NGOs, religious groups and people living with HIV.

Implications:

Findings pointed to how social relations (*jamilii*) manage HIV and infant feeding in complex, dynamic ways, by acting as *kinga* to prevent or permit flow of milk and HIV. Social ties function as social resources within which mothers can exercise social power to widen choices for infant feeding. A mother's social ties function as *kinga* when they are pathways for supplying milk that shields infants from HIV. As such they operate as social capital or 'insurance' (*kinga*) against poverty and limiting choices when "activated by AIDS" (Mtika 2001). Yet this social immunity may also be eroded by HIV. 'Social risks' (Leshabari, Blystad & Moland 2007), such as abuse, neglect, relationship breakdown and social rejection, restrict infant feeding choices (Doherty et al. 2006; Mramba 2006; Rollins et al. 2004), because they block social acceptance and resource and information flow. Social ties can either be agents of shame or protect mothers from it. Close kin, especially fathers, have key positions to protect infants from HIV infection (and mothers from social risks) or hinder such protection. This study also found that fathers, if present, usually act as the first line of *kinga*, being either an obstacle and threat, or a helper and advocate, but not neutral. A mother's networks may practise strategies to avoid shame, such as the private feeding of an infant or providing alternative explanations to observers, and hence enable her to sustain certain infant feeding.

The Swahili concepts described here have influence on infant feeding decisions in the context of HIV and potential use towards social change. Development of categories from Swahili concepts used by respondents themselves recognises that 'our access to culture, knowledge and experiences is mediated by language' (Jordens 2006), including how we categorise and conceptualise the world. These concepts exemplify the 'cultural references and resources' which the United Nations Educational Scientific and Cultural Organization [UNESCO] and UNAIDS. (2001) have called to consider in responses to HIV. Such concepts have been recognised by other scholars as helpful for understanding and communicating information about HIV in Tanzania (Mutembei et al. 2002; Setal 1999). They are useful concepts for education, training and policy, such as clearer presentation of information about HIV and infant feeding and the realities of people's lives. For example, maximising *kinga* could guide assessments of infant feeding choices for women in different situations, depending on her *uwezo*, including her health status and social resources. Core concepts, such as shame (*aibu*), capacity (*uwezo*), safety (*salama*) and openness (*uwazi*) could be used to frame counselling and community conversations because they have more resonance with Swahili-speakers than

concepts such as stigma, income, risk and disclosure. They open up insight into ways of thinking that are particularly Tanzanian and African, and for understanding how people respond to HIV.

Conclusion:

This paper has discussed Swahili conceptualisations which were found to be important for explaining how social relationships in Central Tanzania influence decisions about infant feeding within the context of HIV transmission and infection. Such concepts can be useful for understanding how people respond to HIV as well as be resources for development. It is particularly noteworthy that people in Central Tanzania spoke more often about positive dimensions to more widely embraced negative concepts in Western conversations about HIV, especially ideas of maximising immunity (rather than reducing risk) and building openness (rather than fighting stigma). Such approaches permit nuanced understandings and allow conversations and thinking that focuses optimistically and productively on what capacities are already present in social relations and communities that can be directed towards achieving well-being and safety for children and their mothers.

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