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**Contextualising the Role of Development Support Communicators:
HIV and Infant Feeding Counselling in South Africa**

Abstract

This paper explores the complexities regarding communicating about breast-feeding and HIV transmission in South Africa. Although one-third to one-half of MTCT of the HIV virus may occur through breast-milk, breastfeeding has its benefits (Bertolli et al, 2003) and it is recommended by the World Health Organisation that HIV-positive mothers should practice early and rapid cessation of breastfeeding in order to reduce the risk of transmitting HIV to the child. The suggestion to avoid breastfeeding or early weaning as an intervention to prevent transmission poses a difficult dilemma in regions with developing economies where hygienic replacement feeding is risky, and the practice may be stigmatising, South African is one such country.

Studies have shown that HIV-positive mothers are overwhelmed with their decision-making task regarding infant feeding practices. This paper explores the communication strategies used by counsellors who work with HIV-positive mothers, and seeks to determine the role of Development Support Communicators, as defined by Melkote and Steeves (2001), within the PMTCT programme in South Africa.

The project examines the predominant communication approach of PMTCT counsellors and investigates how their functioning can be improved by the application of participatory processes for empowerment and dialogic decision-making.

Prologue: HIV-Positive Mothers and Infant Feeding

There are a range of debates around infant feeding and HIV in South Africa. The HIV virus has three possible channels of maternal transmission from mother-to-child: in the uterus during pregnancy, during labour, and after birth through breastfeeding. The risk of breastfeeding in particular may increase mother-to-child transmission (MTCT) from between 14 to 29% in developing countries (Chopra et al., 2004: 4). The dichotomy is such that either an HIV-positive mother breast-feeds her child and risks the transmission of the HIV virus through breast-milk to her infant, or in opting not to breast-feed her child, increases her infants' susceptibility to fatal respiratory and gastrointestinal infections or morbidity associated with the mistreatment of formula-feed in preparation and storage. Furthermore, it is the recommendation of the World Health Organisation (WHO) that early and rapid cessation of breastfeeding by HIV-positive mothers should be practiced in order to reduce the risk of MTCT.

In the global HIV/AIDS epidemic, most children who are infected with the HIV virus have acquired the infection through MTCT, in fact, it is estimated that "1700 infections occur through this route each day, most of them in developing countries" (Bertolli et al., 2003: 2089). Moreover, an astonishing "1 in 7 children born to HIV-positive mothers will be infected through breast-milk" (Chopra et al., 2004: 4). The complication with this area of study is that there are many varying factors from case to case that additionally may increase the risk of MTCT. Such factors may include the following: preceding infant or maternal morbidity, duration of breastfeeding, the incidence of mixed feeding interventions, access to proper hygienic health-care and the lack of informational resources.

However, Bertolli et al. (2003) write that although one-third to one-half of MTCT of the HIV virus may occur through breast-milk, breastfeeding has its benefits (2003: 2094). Breastfeeding not only helps new mothers delay subsequent pregnancy, but it also provides immunologic protection and ideal nutrition to the infant (Bertolli et al., 2003: 2094). De Paoli et al. (2008) also warn that the risk of malnutrition, infectious disease and mortality are associated with the effects of non-breastfeeding (2008: 1663). Although Bertolli et al. indicate that in developed countries the avoidance of breastfeeding has been largely recommended to HIV-infected mothers since

replacement formula feeding is safe, affordable and is not stigmatising, the case for developing countries is altogether different.

The suggestion to avoid breastfeeding or early weaning as an intervention to prevent transmission poses a difficult dilemma in regions with intermediate and/or developing economies where hygienic replacement feeding is more risky. In support of this view, Coutsooudis et al., (1999) reported that exclusively breast-fed infants of HIV-positive mothers were protected against infection with the virus (1999: 471). Whereas, in the case of infants who received complementary or supplementary feeding, the virus appeared to pass through the gut barrier of infants and, subsequently, they became infected (Coutsooudis et al., 1999: 471). Coutsooudis et al. (2001) later reconfirmed these findings in a study that demonstrated that infants who were exclusively breast-fed had no excess risk of MTCT over a six month period compared to infants who received no breast-milk but were either formula fed or given other foods (2001: 385). In fact, it was found that infants at the greatest risk of becoming infected with the HIV virus were those who were fed on a mixture of breast-milk and other liquids or foods (Coutsooudis et al., 2001: 385).

Opinions on this topic also include the need to limit the duration of breastfeeding to maximise the benefits incurred, but to reduce the risk of MTCT. The comparatively constant risk of transmission over time indicates that if an HIV-infected mother breast-feeds for a limited time period, for example only six months, then the likelihood of her child becoming infected is reduced by 75% when compared to a mother who breast-feeds her infant for 24 months. Furthermore, if she exclusively breast-feeds for that restricted period, the risk of MTCT may be reduced to an absolute risk of 2 to 4% (De Paoli et al., 2008: 1663). The impetus of this finding alone should be enough to encourage HIV-infected mothers, should they choose to breast-feed, to exclusively breast-feed their infants for a limited duration only.

Mothers who decide to exclusively breast-feed their infants need to determine how and when cessation will occur, how they will implement and support that decision to stop under the possible scrutiny of familial relations and community members, and also how they will deal with infant distress and crying by a child who wants to breast-feed. On the other hand, mothers who decide to formula feed and who never initiate breastfeeding

must ensure they will be able to continually provide formula for their child that is safe and in an environment that is hygienic.

Introduction

With so much information to accept, review and evaluate it is no wonder studies have shown that HIV-positive mothers are overwhelmed with their decision-making task regarding infant feeding practices. The factors for consideration when selecting a feeding practice to adhere to are countless: if infected mothers do breast-feed, the duration must be monitored and the intervention must be exclusive, but if mothers wean or decide not to breast-feed altogether, they must be properly educated on how to prepare, store and feed formula. Many factors come into play regarding infant health but proper training, monitoring and support from counsellors may increase chances of survival if mothers implement what they have learned. If HIV-positive mothers are to make informed decisions that protect the health and rights of their children, counsellors must be effective in providing the appropriate resources and support needed.

The objective of this research project is to explore the communication strategies used by counsellors who work with HIV-positive mothers. Counsellors, as communication vehicles, have an important role to fulfil to ensure the effectiveness of the prevent mother-to-child transmission programmes (PMTCT) in South Africa and for this reason should be specialists in adopting the communication strategies needed to reach the goal of such counselling. The key concerns underlying the motivation of this research are to determine the role of Development Support Communicators, as defined by Melkote and Steeves (2001), within the PMTCT programme in South Africa. The project seeks to examine the predominant communication approach of PMTCT counsellors and how their functioning can be improved by the application of participatory processes for empowerment and dialogic decision-making.

The project attempts to explore such concerns firstly, by reviewing the relevant development communications theory, then by contextualising the role of counsellors in South Africa by comparing two recent studies conducted, then finally, by the analysis of collected data from four qualitative interviews and an electronic email response. In this way recommendations could be made to the role of PMTCT counsellors.

Development Support Communication and Development Support Communicators

Melkote et al. (2001) in *Communication for Development in Third World: Theory and Practice for Empowerment* introduce the notion of a 'Development Support Communicator' into the developmental paradigm of Development Support Communication (DSC). DSC, in the early 1960's, was formulated by a professional UNDP¹ information officer, Erskine Childers. Childers' observation while working in Thailand was that development communication seemed to be "strangely inappropriate" for the socio-cultural setting within which it operated (Ascroft et al., 1994: 276). This resulted in inadequate attention being paid to elements crucial to the effectiveness of a development intervention, such as: "the socio-cultural niceties of development intervention or the delicate nuances of development communication in traditional societies" (Ascroft et al., 1994: 276). The unfortunate consequence of this inattention (as it did in this case) often leads to the failure of a development intervention, this is because the social communication strategies themselves hinder the development that they were created to foster.

Subsequently, Childers proposed a receiver-orientated approach to communication, this mode of communication was to function as a *support* to development initiative specialists in the various technical fields of developmental communications (Ascroft et al., 1994: 276, *emphasis mine*). This approach looks specifically at the receiver of the message and how the message is constructed for that receiver, in order to find ways to *support* the message so that it can be effective and meaningful to the receiver. The approach consists of formulating materials and strategies of communication especially adapted to the needs of specific development projects and communities, and in this way the approach is also tailored to the socio-cultural milieu of the specifically intended beneficiaries (Ascroft et al., 1994: 276).

This new approach to development communication emerged largely from the criticism of the previous ineffective Modernization and Dependency paradigms. James (1994) writes that, unlike traditional development communication of the earlier 'top-down' communication models, DSC is participatory and goal orientated (1994: 332). The overall concerns of DSC as a paradigm are: "communication at the grassroots, message

¹ United Nations Development Programme

structure, message effects, and the ability of the target group to process development information effectively” (James, 1994: 332). Furthermore DSC, as a renegotiation of Modernization and Dependency, operates as a mediator between national development strategies and local communities (Tomaselli, 2001: 8). DSC while acting as a mediator *legitimises outside input* into a community by the presence of a Development Support Communicator, who is the facilitator of participatory development coming from the ‘bottom-up’. This is important because, despite tending to obscure the agendas of donors, DSC has also been effective in bringing innovations to beneficiary communities (Tomaselli, 2001: 10).

The objective of these Development Support Communicators is to work with individuals and communities at the grassroots level, in the hope that they may eventually not only enter but also participate meaningfully in the political and economic processes of their societies (Melkote et al., 2001: 356). There is also a large emphasis on the work of Development Support Communicators to foster the process of empowerment through the co-sharing of knowledge and in doing so, encourage participatory decision-making for the benefit of those at the grassroots. A Development Support Communicator, according to Melkote et al. (2001), should function for the people as an advocate, a communication channel, a consultant and a promoter of the interests of the community. Ascroft et al. write that a DSC professional should be skilled at creating the understandings of complex issues needed for people to make informed development decisions (1994: 278). In other words, Development Support Communicators, such as HIV and infant feeding counsellors, should aim to communicate the complexities of different infant feeding practices and their associated transmission risks to HIV-positive mothers in a manner that empowers the mothers with understanding to make appropriate choices for themselves and their infants, in this way horizontal communication between two equal parties is achieved.

The role of a Development Support Communicator when performed correctly must be to generate the conditions, situational and psychological, in which development benefactors and intended beneficiaries can participate mutually with co-equality in making development decisions (Ascroft et al., 1994: 310). Although the Development Support Communicator plans and executes the development intervention, along with the knowledge and help of the communities they seek to empower, the end goal is to hand

over the development initiative to the community entirely and for the role of the Development Support Communicator to eventually become redundant (Melkote et al., 2001: 363).

Renegotiating Modernization and Dependency

DSC emerged as a middle path between Modernization and Dependency theory to address the criticisms of two flawed development paradigm trajectories (Tomaselli, 2001: 8). The following section discusses each paradigm separately:

The Modernization Paradigm

Modernization theory was based on liberal political theory, and originated in the overall doctrines of Western attitudes as articulated through the 'Enlightenment Era', namely reasoning, rationality, objectivity and other philosophical principles of Western Science (Melkote et al., 2001: 71). Subsequently, the Modernization paradigm, in relation to its application in the context of Third World development, has been criticised for being abstract, ahistoric and inappropriate (Dyll, 2009: 21). According to Servaes (1996) the dominant belief of Modernization is that development can be motivated by external and endogenous factors, such as imposed Western beliefs and practices, this development can then be supported by internal measures to achieve modern societies and modernize traditional sectors.

Modernization, applied to areas outside of the West, was achieved by importing a Western neo-classical economic model for capitalist development. Indeed, economic backwardness was ascribed to the inherent traditional values and institutions within the community core which were unlike Western systems (Melkote et al., 2001: 181). Therefore, Modernization worked to substitute values and beliefs that were incompatible with modernity, which was from a Western perspective characterised by science, technology and the ideology of progress to foster development (Melkote et al., 2001: 181). Moreover, the key objective of Modernization was then to convert the Third World by replacing non-Western (tradition) systems with more 'superior' Western systems, and this operation was largely conducted by the work of change or extension agents and the use of mass media.

Within Modernization, the local-level framework to guide intervention planning gradually evolved from the diffusion of innovations theory (Melkote et al., 2001: 120). Diffusion of innovations theory was proposed by Rogers (1962) who regarded development as a type of social change in which new ideas and innovations were introduced into a community system with the aim to produce higher levels of income and living through the application of more modern production methods and improved social organisation as prescribed by the West. The development process within Modernization, therefore, was understood as the communication and acceptance of new ideas, innovations and technologies from external sources – an exogenously induced change (Melkote et al. 2001: 122).

Five steps were conceptualised in the course of diffusionist theory to explain the adoption process of suggested change by extension agents, namely: awareness of innovation, interest to seek more information, evaluation and trial of the innovation and, finally, adoption (Melkote et al., 2001: 123). Often the persuasion of an opinion leader or an influential member in the community to adopt an innovation increased the likelihood of the rest of the community also accepting the change. The assumption here was that information was the missing link to the adoption of a particular practice or belief in a certain set of values. This assumption causes the failure of health communications merely because believing that if people knew better they would conduct their lives in a healthier manner, is simplistic and naïve.

The Dependency Paradigm

Dependency or Dissociation theory grew from the critique of Modernization mainly by theorists from South and Central American movements. Such critics argued that because Modernization persuaded individuals to rid themselves of their un-progressive traditions by internalising consumer behaviour and attitudes, the outcome of their 'development' was in reality actually continued dependence on and domination by the West (Bah, 2008: 797). Frank (1981) was an influential critic who claimed that the Modernization perspective was empirically unsustainable and theoretically insufficient, which was in a practical sense unable to stimulate development in the Third World. Subsequent to these accusations posed against Modernization, in the late 70's, was a paradigm shift in development communications from the dominant Modernization

paradigm to the Dependency paradigm, which was named more for what it denounced than for what it proposed (Bah, 2008: 797).

The major components of Dependency theory in disagreement with the propositions of the Modernization paradigm, according to Servaes (1996) are as follows:

1. The process of development is analysed in terms of relations between regions, central and peripheral.
2. The most important obstacles to development are external to the underdeveloped nation.
3. Due to the fact that the periphery is deprived of its surplus, development in the centre implies underdevelopment in the periphery.
4. It is necessary for a peripheral country to dissociate itself from the world market and strive for self-reliance. (1996: 84)

This means that development must be viewed as interrelated and connected to underdevelopment and that the two are differing measures on the same scale. Dependency theory held that in order for the 'periphery' to develop it must cut off all dependence on the 'centre' and rely on its own local resources and internal traditional structures to carry its progress and modernization.

Following this movement in development communication, was the emergence of a third paradigm which criticised Dependency for its idealism and failure to account for the role of power, whether institutionalised externally or internally, since the presence of power relations still implies some form of domination and subsequent dependence. The result of such criticism has been referred to as DSC which is based on an empowerment paradigm that advocates a participatory approach to development (Bah, 2008: 798).

Communication or Extension: The Communication Process

The communication process when simplified essentially has three key components, as is represented in the traditional sender-receiver (S-R) communication model proposed by Shannon and Weaver (1969). In the linear process a sender transmits a message in a shared language to a receiver to be decoded and made meaningful. Later modifications

to the S-R model of communication accommodate the need for a system that includes a channel for feedback from the receiver of a message to the sender. In developmental communications such as health promotion, a counsellor or health worker could be seen as a sender of a particular health message and the receiver would then be the patient who hears and decodes that message. Although this communication process may vary in effectiveness, it is the standard progression of dialogue in most communication professions.

Furthermore, Melkote et al. (2001) assert that Development Support Communicators have a niche role to fulfill regarding developmental communications which is different from that of a development specialist or extension worker:

The DSC professional is not a development specialist like agricultural extension or health extension workers. Extension workers are primarily subject matter specialists in agriculture, health, or nutrition, usually with only a smattering of training in social-scientific communication techniques. They also lack a sufficiently broad education in the social sciences and humanities to observe and appreciate socio-economic and cultural barriers to empowerment. This makes most extension personnel ineligible to act as advocates for the people. (2001: 360)

This is an important distinction to be made, especially in the field of health communication where the most normative practice of disseminating information tends to be 'top-down' and authoritarian with the purpose of behavioural change by the coercion of change agents. A change agent is an extension professional who endeavours to sway adoption decisions in a direction that he feels desirable (Rogers, 1962: 17). The extension system within the Modernization paradigm used such agents to decide what innovations were best for its clients, and then followed such enforced decisions with campaigns intended to convince the clients of the wisdom of that choice (Melkote et al., 2001: 56).

The contention here is that the extension model is a one-way communication strategy that is concerned primarily with extending influence and imposing knowledge or technical ability onto a community, whereas communication should involve mutual dialogic participation (Freire, 1993). Robert White asserts that communication is not centred on the manufacture of definitive messages to be transferred by a powerful

source to passive receivers, but it is seen as a continual process in which all are seen as transmitters *and* receivers (2004: 17, *emphasis mine*). It is for this reason that the space in which the communication process unfolds should be a space which is opened for a more participatory, dialogical, non-directive and horizontal type of communication (White, 2004: 17). Because information can be disseminated but knowledge cannot, the heart of any participatory process is that communication must be based on the premise of sharing knowledge (Decock, 2000: 131). This mode of communication will enable all in the group to gradually enter the decision-making process to make a contribution to the collective action (White, 2004: 17) and in this way, participation becomes the tool by which the intended beneficiaries are activated to accept a specific development intervention or programme (Riano, 1994: 50).

Ascroft (1994) further contrasts extension and communication stating that:

Information sharing [communication] from person to person, community to community, nation to nation is the stuff of human advancement, a mutually beneficial activity. Without it, we would still be fashioning tools of stone. But influence peddling [extension], especially the supplantation of ideologies, is often the stuff of acrimony and adversity. (1994: 249)

Communication, not mere influence peddling, must be motivated by the two-way co-sharing of knowledge in order for it to be considered genuine communication. Servaes (1996) writes that development workers should respond to the specific communities they work with, in a manner relevant to that context, in an attempt to aid the empowering process rather than adopting a prescriptive approach. It is vital that then the emphasis is on information *exchange* rather than on persuasion from the top-down as in the diffusion model (Servaes, 1996: 77). This fairly recent progression within the field of development communication has emphasised the notion of knowledge sharing, leading towards the increased chance of benefactors and beneficiaries having the equal opportunity to participate in influencing each other. Importantly, over and above what theorists may propose concerning communication approaches, is that communication on a co-equal basis is actually ethically correct, practically relevant and useful, and promises a more democratic forum for communication as it supports the *right to communicate*, which of course is a basic right of all peoples (Melkote et al., 1994: 315).

Therefore, since the heart of this communication process is two-way, it can then be considered as participatory by nature. In the light of this, consider the words of former Tanzanian president, Julius Nyerere:

People cannot be developed; they can only develop themselves. For while it is possible for an outsider to build a man's home, an outsider cannot give the man pride and self-confidence in himself as a human being. Those things a man has to create in himself by his own actions. He develops himself by what he does; he develops himself by making his own decisions by increasing his understanding of what he is doing, and why; by increasing his own knowledge and ability, and by his own full participation – as an equal – in the life of the community he lives in (1973: 60).

Servaes agrees with this notion of people developing themselves, as articulated by Nyerere, by stating that “self-management” is the most advanced form of participation (1996: 79). Furthermore, Ascroft et al. (1994) write that development is largely based on voluntary change but people are unlikely to change willingly unless they *participate in deciding* the nature of the change expected of them (1994: 279, *emphasis mine*). The goal of Development Support Communicators is then to encourage this process of self-management and enable people to help themselves, which according to Servaes (1999) is also the foundation of the empowerment process.

Development Support Communication and Empowerment

Empowerment is: “a process in which individuals and organisations gain control and mastery over social economic conditions, over democratic participation in their communities and over their own stories” (Melkote et al., 2001: 37). Empowerment is conceptualised as enabling, which is essentially acquiring knowledge and status to take control of one's own life, it is the capacity to benefit from involvement of a development initiative (Riano, 1994: 7). For the purposes of this paper, genuine empowerment is also regarded as developing the individual and collective capacity of communities and persons to impact change in their own lives, in this way the process leads to increased ownership and control (Riano, 1994: 7).

Melkote et al. (2001) also assert the belief that real social change cannot be achieved in our current societies unless power inequalities are directly addressed. In light of this, Servaes argues that *authentic participation* directly challenges power distribution in our

societies (Servaes, 1996: 76). It is for this reason that Development Support Communicators should engage those with whom they communicate in participatory decision-making and knowledge sharing to foster the process of empowerment by redistributing power to those who are powerless. These are noteworthy communication strategies, according to Robert White, because one of the most significant moves towards empowerment is handing decisions back to development beneficiaries themselves (2004: 12).

Moreover, Shirley White (1994) flags the importance of conscientisation, writing that empowerment is realised through this process (1994: 25). Conscientisation is, according to Freire (1972), the process by which oppressed peoples are able to activate their consciousness and critical awareness regarding their situation, environment, identity, talents, and alternatives for freedom of action and so on. It is also essential to participatory action. The process of conscientisation can become focused through participatory processes which increase understanding and a sense of control, both of which are crucial for having input into the development decisions made by communities (White, S. 1994: 25). These processes in the case of Development Support Communicators in health communication can be included in their task as consultants or as links to informational resources.

The joint guidelines issued (first in 1998/9 and then updated in 2000) by WHO, UNAIDS² and UNICEF³ specifically emphasise that: “All HIV-infected mothers should receive counselling, which includes the provision of general information about the risks and benefits of various infant feeding options, and specific guidance in selecting the option most likely to be suitable for their situation. Whatever a mother decides, she should be supported in her choice”. In countries participating in the initiative sponsored by WHO, UNAIDS and UNICEF to PMTCT, the goal is to *empower* HIV-infected women to make informed choices about whether to breast-feed or use breast-milk substitutes. This can be done through the work of effective counsellors who, unlike prescriptive extension workers, support women in their decision-making by including them in mutual dialogic communication.

² United Nations Programme on HIV/AIDS

³ United Nations Children's Fund

A further consideration is that many of the medical recommendations made by PMTCT programmes are often difficult for women to implement because of community norms, values, and beliefs. For example, taking medication during pregnancy and using breast-milk substitutes or practicing exclusive breastfeeding and then early weaning are not normative practices for women, especially in rural areas of developing countries (Baek et al., 2007: 4). It is for this reason that counsellors must become the bridge to implementing culturally 'foreign' practices, so that the individuals they counsel have sufficient self-confidence to make choices and to demand their rights (White, 1994: 25).

Contextualising Counselling in South Africa: A Comparative Look at Two Studies

Currently in South Africa, HIV-infected mothers are encouraged to choose either exclusive breastfeeding for six months then complete cessation, or exclusive replacement feeding from birth. However, this decision is often made by mothers with little information or understanding as to how they are to go about implementing their chosen infant feeding practice. In 2002 the PMTCT intervention was introduced nationally to 18 pilot sites across the country and after the initial evaluations these sites were given further resources to increase efficiency. The resources were used specifically at such sites to employ lay counsellors, to conduct rapid HIV tests in antenatal clinics, and to provide free formula for at least six months for those who chose not to breast-feed. Counsellors at all these sites were given training lasting at least two weeks. The training covered issues of HIV counselling including voluntary confidential testing (VCT) and counselling for infant feeding, although the latter was only very briefly covered and usually given less than one day (Chopra et al., 2005: 358).

A prospective cohort study conducted by Chopra et al. (2004) to evaluate the quality of counselling provided to mothers at the PMTCT pilot sites in South Africa was focused through a critical look at three specific sites representative of a cross-section of psychosocial demographics in South Africa. Chopra et al. (2004) conducted the study with 60 HIV-positive women who attended routine PMTCT services (in Paarl, Umzimkulu and Umlazi) by structured observations of consultations and exit interviews. Across the three sites 22 counsellors were also observed, including lay counsellors and nurses. The study found that overall while communication skills of counsellors was fair, the actual quality of infant feeding counselling was poor with inadequate information provided for

women to make suitable choices. The evidence of this is summed in a few key findings discovered across the three sites:

Only two HIV-positive mothers were asked about essential conditions for safe formula feeding before a decision about an infant feeding option was made. None of the twelve mothers choosing to breast-feed were shown how to position the baby correctly on the breast or asked whether they thought exclusive breastfeeding was feasible. Fewer than a quarter of mothers expressed confidence in performing the actions required and 85% could not define the term exclusive breastfeeding. (Chopra et al., 2004: 3).

Not only was it established from this study that women were provided with incomplete information about PMTCT and feeding practices, counsellors were also found to be lacking confidence to fulfil their roles in a way that was appropriately meaningful and influential. It was found that counsellors lacked the skills to take mothers through the logical process of assessing home circumstances and to present risks to infected mothers in a manner that assisted them in making a suitable infant feeding choice (Doherty, 2007: 1). Unsurprisingly, the site that performed the best in the evaluation was the one which had received the most supervised support and training. It was also found that across most sites women are unwilling to disclose their HIV status due to discrimination and as a result were hindered in their ability to adhere to infant feeding advice and to seek support from relatives or other community members.

This study highlights two main areas of HIV and infant feeding counselling that need to be readdressed, firstly, that of content, and secondly, approach. Both of these areas are informed by the level to which counsellors have been trained to effectively fulfil their roles as communication specialists who act in a way as to support the development of a mothers' ability to identify and resolve her own problems. For this reason, it is important that counsellors are trained *how* to empower those with whom they communicate by linking them to resources such as facilities, information and authorities. Counsellors should also be competent in their ability to create and maintain a two-way flow of communication between themselves and the communities they seek to help, and in this manner, to foster participatory decision-making by engaging mothers in an equal flow of knowledge co-sharing.

A more recent qualitative study conducted by De Paoli et al. (2008) sought to assess breastfeeding cessation as part of a MTCT prevention strategy recommended by WHO and found overall that counsellors admitted to having limited practical advice to guide mothers on infant feeding practices. De Paoli et al. conducted in-depth interviews with 16 HIV-positive mothers and 13 PMTCT counsellors who were recruited from four peri-urban provincial government clinics and one PMTCT intervention research site in Durban, South Africa. HIV-positive mothers who were recruited had infants between 4 and 7 months of age, these mothers were interviewed through the process of their infant feeding planning, as well as while they were undergoing and once they had achieved breastfeeding cessation. This was done to assess the way in which the mothers adhered to their chosen infant feeding intervention and the support that they received from PMTCT counsellors to do so.

There was a notable difference found between the research site and the provincial health clinics, it was found that at the clinics there was minimal continuity of care, and counsellors subsequently battled to refer mothers to participate in the study because they rarely knew how the mothers intended to feed their infants. At the research site, PMTCT counsellors who had contact with breastfeeding HIV-positive mothers could introduce the study and then encourage interested mothers to enrol to participate. Those same counsellors then became a part of the process and assisted the participating mothers in their antenatal choice of feeding and were routinely available for support and guidance in breastfeeding practices and cessation (De Paoli et al. 2008: 1664).

The results of particular interest to this project revealed the role and impact of counsellors in HIV and infant feeding counselling as follows: De Paoli et al. found that 7 of the 13 counsellors interviewed practiced approaches that were judgemental and coercive, one counsellor said in an interview: “after we [counsellors] have explained the difference between exclusive breastfeeding and infant feeding formula then we make a choice for them” (2008: 1664). This represents an authoritarian approach to counselling that is top-down in its attempt to disseminate only information. It is ineffective communication such as this that does not foster participatory decision-making or empowerment, and the likely result, as was found in the study, is non-adherence to proper infant feeding guidelines.

Another hindrance to the quality of counselling reflected in the study is the timing of the communication that occurred between counsellors and mothers at the participating sites. HIV-positive mothers who had been counselled at the clinics reported that they had been counselled on infant feeding practices on the same day that they had received their positive HIV test results. These mothers indicated that it was hard for them to concentrate at that time on any other information given by the counsellor (De Paoli et al., 2008:1665). For this reason, the most compelling evidence that this communication strategy is ineffective is shown in the fact that the majority of mothers who participated in the study were still confused about the various feeding practices post-counselling. Not only did most of the mothers have no awareness of the risks involved in the practice of replacement feeding, but it was also reported that often mothers stored prepared formula milk for long periods, during which time it could become contaminated. De Paoli et al. go on to state that there was little understanding of the rationale for rapid cessation of breastfeeding and why there is an increased risk with continued breastfeeding beyond six months of age. Furthermore, only four of sixteen mothers were clear about the reasoning for what they were doing with regard to the implementation of exclusive breastfeeding and then cessation as a feeding intervention (2008: 1665). One mother interviewed for this study said:

I know that it [rapid cessation] is not a 100% method, and they [counsellors] also told me that if I practice mixed feeding that it is also not good for the child. But, they did not explain why. The only thing that I would like to know ... which was never explained to me, is, what exactly happens if I practice mixed feeding? *I want the facts to why I was told to do what I have been practising, what I should and should not do and what is safe for my child.* (De Paoli et al., 2008: 1665, *emphasis mine*)

De Paoli et al. also reported that most of the mothers experienced loneliness and despair in the cessation period and received minimal support from home which occurs increasingly because of stigma and discrimination. A few mothers also mentioned that they found regular follow-up visits a positive and encouraging experience which implies that the role of a competent caring counsellor is vital not only to adherence, but also to the mental well-being a mother (2008: 1665). Moreover, even though the support received from counsellors was not optimal, it was meaningful and influential to the mothers. Both mothers and counsellors at the research site were optimistic and this is largely a result of the fact that the women were regularly informed on infant feeding and

supported during antenatal visits. However, at the clinics women who routinely visited rarely approached the counsellors for support and the counsellors generally doubted the abilities of mothers to adhere to cessation and tell them the truth about what was happening in the home environment (De Paoli et al., 2008: 1666-1667).

Methodology

The research conducted for this qualitative study was performed by using the methods of electronic questionnaires with an open-ended component and unstructured interviews. The nature of this research topic was best served by a qualitative approach, since a qualitative understanding of how society mediates action is not achieved optimally by the techniques of quantitative research in which a researcher can know only numbers (McCracken, 1988: 9). The questionnaire which was to be self-administered, was distributed electronically via email to a list of 12 professionals within the field of HIV and infant feeding research, these professionals were the researchers who conducted the studies which formed the basis of this project. Unfortunately, there was only one response to the electronic questionnaires, but such obstacles can be expected in most forms of research and when conducting research one should not be absolutely rigid as in practice it is most likely that the researcher will deviate from a proposed plan anyway (Batten, 1971: 204). The planned analysis for the received questionnaires then had some revision since a comparative analysis across all the questionnaire responses was not a feasible option. Instead, the open-ended component of the questionnaires was used as a complement to the thematic analysis of the data from the interviews conducted.

The unstructured interview was used in this project because the interview participants were all themselves experts and professionals in the field under investigation, either as HIV researchers or as counsellor trainers and supervisors or as counselling professors. The assumptions that underlie the unstructured interview are that the relevant dimensions that will be discussed will emerge in the course of the interview, that the participant is more knowledgeable than the researcher about the issues to be discussed, and lastly, that the lack of structure will lead to greater richness in data (Howard, 1985: 217). These participants were chosen since they were accessible to the researcher, whereas the HIV-positive mothers themselves, due to ethical implications, were not.

Four long interviews were conducted, with a mean time of 44 minutes per interview. The interviews were digitally recorded and then transcribed by the researcher who conducted the interview.

Only four interviews were conducted because it is more important with qualitative research to work longer and with greater care with a few people than superficially with many participants (McCracken, 1988: 17). In terms of reviewing the transcribed data, the object of analysis was the establishment of patterns of inter-theme consistency and contradiction between the four different interviews (McCracken, 1988: 42). The final part of analysis in this project, by using theory and literature as a template in relation to found data, was to offer through critical considerations, recommendations to the role of counsellors in South Africa. In this way, the analysis moves from a broad perspective to a narrow focused view of the object under examination in order to fulfil the aforementioned research objectives as outlined in the introduction.

Research Results and Analysis: Who says What, to Whom and How?

In the analysis of the transcribed interviews conducted and the response to the electronic questionnaire several of the same concerns and issues around HIV counsellors and infant feeding counselling in South Africa emerged. These concerns and issues that became evident throughout the research process not only supported the results of other previous literature, but also could be grouped into similar thematic topics for discussion. The three topics found were: (a) the communicators, (b) the message, and (c) the receiver and the context of reception.

The Communicators

It was found that all respondents had anxieties about the level to which counsellors possessed the ability to put aside their own personal values that may be informed by social stigma and discrimination. Respondent 1 had particular concerns about how a counsellor transcends a very real moralistic positioning with regard to their own personal feelings of HIV/AIDS. Respondent 1 indicated that in the counselling process there is inevitably an initial sort of judgment that takes place which can be a difficult response for the counsellor to subject and overcome. This initial judgment becomes problematic when

a counsellor cannot separate it from their steering of the patient or client. Respondent 3 also had similar comments noting that it may be too optimistic to believe that counsellors who have received little training will know how to deal with their own prejudices. According to Respondent 3 it is very difficult for even trained psychologists to deal with their own prejudices, how much more would this difficulty increase for a counsellor if they have not been trained in that specific discipline. Respondent 4, who was involved in supervising HIV counselling students, said that the students' biggest obstacle was that they battled on a personal level to deal with their own issues as well as assisting patients or clients with theirs. It is for this reason that Respondent 4 indicates the need for a level of maturity when one decides to enter the profession of counselling:

When you are dealing with people's emotions and any form of trauma in an individual's life, you yourself, I think have to be mature enough, have the insight, have the knowledge, and I think a level of awareness – self-awareness to walk this journey with that particular individual who is going through a tough time. We are looking for people who have the ability to cope. Again it's a very broad term, what do you mean by coping skills and strategies, it's the ability to be aware of what your own limitations are, aware of what your strengths are because through that awareness you not only grow within the [...] relationship with your other colleagues and your peers [...] but you also begin to grow with that particular client or patient. (Respondent 4, 2009: Interview)

The notion of prescriptivist communication, at this level, becomes very real since an immature counsellor may rely on moralistic positioning to disseminate health advice and replicate the role of a change agent as in the Modernization paradigm. There are counsellors in the field, according to Respondent 4, who would prefer their patients or clients "to do it their way" and this is because of their personal perception that they know better than the client and therefore the client should simply adhere to their advice, whether it is appropriate or not (2009: Interview). In support of this, Respondent 2 says from her experience, that governmental HIV counsellors go for only one week's training after which they are:

[...] put in clinics, they never see anybody, no-one follows them up, no-one knows what they doing and they talk the biggest load of rubbish – they just use their own feelings – *if they are for formula they'll push formula, if they for breastfeeding they'll push breastfeeding*. They don't waste their time with the special counselling you supposed to do, it's called infant feeding counselling [...] There's the AFASS criteria, it's [the conditions for formula feeding] got to be acceptable, feasible, affordable, sustainable, and safe. Most counsellors do not even have the vaguest idea how to do counselling, they don't know what they doing and so they

just do nothing and make a mess. So now, I've got this new thing, where we've chosen five of these AFASS criteria which are South African relevant where we know that if that is not in place, formula feeding is not safe. Literally, have just said: go through each of these, if not all of these five are ticked, formula feeding is not safe, do *not* recommend it. (Respondent 2, 2009: Interview)

Although Respondent 2 believes that the effectiveness and outcome of a programme rests on the competency of counsellors, Respondent 1 disagrees stating that it would be too simplistic to assume that if counsellors did their job better that the results would be different within the context of South Africa, since the missing link is not the lack of information in the development process. Respondent 4 believes that while this is a valid point to some extent, one must also consider that a counsellor can only do so much, after which a patient or client must be responsible for their own decisions-making and adherence:

[...] As a counsellor you have the information, the knowledge that you need to convey to particular people. [...] Once that information is conveyed you have done what you needed do to, the best that you could do. It does boil down to the individual and their choices. It's about acknowledging that that individual needs to live their life the way they choose and that there is no hang up on what is right and what is wrong because that is where the lines get blurred and I think that is where we get it complicated. (Respondent 4, 2009: Interview)

Within HIV and infant feeding counselling, counsellors must take responsibility for ensuring that the mothers whom they counsel have a degree of understanding to support the information that they have received. In terms of counsellor responsibility, "it's about acknowledging that when you are in that seat and counselling, there particular ethical rules [...] you need to adhere to, you also have personal and private 'stuff' that you need to be aware of so that does not interfere in the process of helping that individual and assisting them in the best way you that you can" (Respondent 4, 2009: Interview). It is important to note, as Respondent 5 raised, that merely because mothers may *listen* to health personnel, this does not necessarily mean that mothers will *understand* the information being given to them and *adhere* to the advice of counsellors. Infant feeding counselling, to rectify this and to minimise the opportunity for misunderstanding, must be an open dialogue between a mother, her close social network, and a *skilled* counsellor. The reality is that the only function that can be expected of a counsellor who has received minimal training is simply to be able to

provide mothers with different alternatives but with no real understanding or knowledge about application of that information (Respondent 3, 2009: Interview).

The Message

The clarification of the message of infant feeding counselling goes hand-in-hand with the ability of counsellors to relay a message and their responsibility to ensure understanding. This ability is linked to the training that counsellors have received to allow them to fulfil their roles meaningfully and influentially. All of the respondents believe that the process of training counsellors to carry messages well relies on how counsellors are selected in the first place. The kind of person that should be selected must be competent enough to think critically about their training and be able to apply it to a whole myriad of circumstances, because for every mother that they assist the application will be different. A good counsellor is someone who can stay with the story of a person and really understand why they have come for assistance, a person who can help mothers to see the various solutions to solving their decision-making dilemma (Respondent 1, 2009: Interview).

Essentially, infant feeding counselling is not simply telling mothers what to do, but it is helping mothers make their own decisions around the possible alternatives. And in order for mothers to know what decision would be best suited for their capabilities and domestic circumstances, they must have information. So the counselling process becomes about empowering mothers with the ability of “informed decision-making” by including them in the co-equal sharing of knowledge and listening to their stories (Respondent 3, 2009: Interview). The role of a counsellor should be as only a facilitator in this process who, in handing the decision to the beneficiary, encourages them to participate in their own personal process of coping with the virus and being concerned for their infants’ health.

The selection of counselling candidates must also take into account communication skills, level of education, willingness to be supervised, cultural awareness, and a real desire to help people. Respondent 2 goes as far to say that if counsellors are not selected properly then they are “un-trainable” to communicate the message (2009: Interview). Moreover, Respondent 3 highlights the need for a rigorous screening

procedure to address the concern that lay counsellors who come forward to receive training may just apply because they see the work as simply an employment opportunity. This, of course, is problematic because the intention of such applicants would be to complete their work only to receive a salary and not to actually assist people. But unfortunately, even those who have good intentions in becoming counsellors do as much harm by mis-communicating the intended message:

I think it is about intention, for some individuals the intention is clear that we [counsellors] are assisting and helping, however, the knowledge that they have been provided may not be up to date or may not be communicated effectively [to them as counsellors] so that they fully understand what they are now conveying to the people that they see. So even though there are some with good clear intentions it's about where is your knowledge base coming from and are you supported, are you kept up to date with the latest trends, and information and research to assist the community. (Respondent 4, 2009: Interview)

For Respondent 3 over and above the inability to communicate a message interfering with the communication process is the fact that there are too many messages regarding infant feeding, particularly around different techniques, exclusivity, durations and practices. Respondent 5 stated that in addition to the overload of information that mothers receive, she believes that the reason for mothers' poor knowledge of infant feeding practices post-counselling is because: (a) the time a mother spends, on average, with counsellors is not enough, (b) most counsellors do not have sufficient knowledge about infant feeding issues and are not updated regularly, (c) mothers are seldom followed up by the same counsellor and, finally (d) mothers are counselled about infant feeding commonly for the first time only when they are diagnosed as HIV-positive. The setup of PMTCT services are to blame for the ineffectiveness of PMTCT communications because they are a barrier to the message which should actually ensure that a women is "counselled to *her choice*" of feeding practice (Respondent 1, 2009: Interview). In these cases, there is no resultant empowerment after the counselling as the process does not ensure that "people are able to help themselves" (Servaes, 1999: 194).

One of the ways to ensure that there are no information gaps in the actual content of the message that counsellors communicate to mothers is to have ongoing training regarding PMTCT strategies. Respondent 4 indicated that coming into contact with counsellors she discovered that they felt as though they needed ongoing training to overcome their

personal limitations. Respondent 2 found that the counsellors she worked with in her programme were eager to learn more in addition to what they were expected to know, and their effectiveness was greater because of their increased knowledge of various psycho-social and medical issues. Counsellors have the role of *interpreting complete* communication messages regarding PMTCT from WHO, governmental policies, and other medical authorities to empower women with information. Counsellors should be aware of the national breast-feeding and infant feeding policies and be continually updated about changes and recommendations. Respondents also raised another important aspect regarding the message saying that institutional support and resources to back it up will not only give the message credibility, but will also encourage adherence.

The Receiver and the Context of Reception

Besides the inability of a counsellor to relay a particular health message effectively, inadequate training, and poor construction of the message, the receiver and the context within which they receive a message can also be barriers to the communication process. It is important to note that the reception of the message on a personalised level for individual mothers will be influenced strongly by her beliefs, values, and domestic circumstances. The communication model in DSC takes this into account in its receiver-orientated approach emphasising that the conditions of message communication should be tailored to the receivers and to their context. Without a receiver and a context in which to be understood, a message from a counsellor would be a useless tangle of wordy advice. An infant feeding counsellor is, by communicating a message, trying to elicit a response from the mothers that they counsel to select a feeding behaviour that will be suitable to her situation. According to Respondent 3, “you can’t change any behaviour unless you understand the underlying determinants of that behaviour”, therefore counsellors must have some idea of the motivation that drives women to select and adhere to certain infant feeding practices and counsel them accordingly (2009: Interview). For example, “if it is fear of stigma [that causes them to breast-feed instead of formula feed], it’ll mean how best to deal with that fear, how best to deal with the possibility of being discriminated against; if the fear is about conflict, then the counselling will need to move into another domain of conflict resolution and other dimensions” (Respondent 3, 2009: Interview).

The other major consideration regarding the context of reception entails the prevalent collectivist culture evident in South African communities, this is vital because: “it’s not one person making a decision [regarding feeding practice], so it’s about how to involve others and deal with the tension of confidentiality” (Respondent 1, 2009: Interview). Respondent 4 indicates the same tension, in the counselling practice in South Africa, noting that mothers will often make a decision based on what their broader network might advise without taking into account proper medical issues in and around infant feeding. Development is based on voluntary change but people are unlikely to adopt development decisions made unless they themselves and their close networks are included in deciding the nature of the change expected of them. This must be taken into account when implementing a contextually sensitive counselling approach relevant for South African communities.

Recommendations

Based on the research with the medical professionals, counselors and programme managers above, there are some obvious problems with the current PMTCT counseling programmes in clinics. These practical considerations fit with the literature around development support communication, and suggest a more empowering communication approach is necessary. The research findings suggest the following recommendations for future programmes:

- 1: A more rigorous selection and screening process should be implemented to ensure that counsellors are competent and capable.
- 2: Training for counsellors should be standardized perhaps by accrediting specific infant feeding courses and workshops so that the quality of training can be monitored. Training should also be lengthened and conducted on-site.
- 3: Training should include a problem solving component where counsellors are trained how to practically apply their knowledge to various situations representative of the issues that they may encounter while they are in the field. In this way, those who train counsellors should aim to build the confidence of counsellors.
- 4: Counsellors should be supported within a mentorship system of collective sessions with other counsellors, health-care professionals and trained psychologists on a regular basis. In such sessions, counsellors should be encouraged to discuss any difficulties

they may be facing either on a personal level, such as how they are coping, or with particular patients.

5: The timing of infant feeding counselling should be reconsidered, or repeated at a later stage when mothers can think clearly. Counsellors must be aware of mothers' vulnerability and emotional state when they communicate infant feeding messages.

6: A system of support should be implemented for mothers, where they are encouraged to disclose to family members or close friends, so that they may receive support from their own networks. Alternatively, mothers could be put in contact with other mothers who have successfully selected and adhered to a specific feeding practice.

7: Mothers should have regular contact with the same counsellor throughout the duration of the feeding intervention to encourage a mutual relational trust and respect for one another.

8: A collectivist sensitive approach to counselling should be considered as a means to reduce stigma and increase close network support for HIV-positive mothers.

Conclusion

This project has revealed that the role of counsellors in infant feeding counselling cannot be over-emphasised considering that qualitative research has proven that women, especially those infected with HIV, rely heavily on the advice of health workers to guide their feeding choices (Doherty et al., 2006: 27). Kassier et al., (2003) affirm this position saying that the fact that clinic based nursing staff are the most important source of infant feeding information, both antenatally and postnatally, underlines their important role in shaping appropriate infant feeding decisions (2003: 23). And while the recommended messages about feeding interventions are applicable, they are also somewhat impractical and the women affected may be in need of guidance with additional counsellor and health service support. Therefore, the feeding recommendations should be specifically reconsidered in the case of developing countries where resources are limited and PMTCT guidelines cannot be fully achieved.

The research conducted for this project, as well as the review of previously published literature, has shown that counsellors have a specialised niche role within health communications in South Africa. Although the current PMTCT communication

approaches at work in South Africa lack meaningful and significant input into the lives of HIV-infected mothers, for all the above reasons discussed, counsellors *can* greatly increase the effectiveness of the PMTCT programme in South Africa when they function optimally. Therefore, this project has recommended the role of a Development Support Communicator, in character and approach, for increased success of the communication strategies used in HIV and infant feeding counselling for empowerment and participatory decision-making.

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Respondent 2: Anna Coutsooudis: Medical School at the University of Kwa-Zulu Natal.

Respondent 3: For the purposes of this project Respondent 3 wished to remain anonymous.

Respondent 4: For the purposes of this project Respondent 4 wished to remain anonymous

Respondent 5: For the purposes of this project Respondent 5 wished to remain anonymous

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