When a prevention policy leads to economic vulnerability: the case of PMTCT in Senegal

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Abstract: When, in 2010, a new PMTCT (Prevention of Mother-to-Child Transmission) strategy replaced the provision of infant formula to mothers living with HIV by a prophylaxis based on antiretrovirals, some Senegalese couples decided to purchase infant formula on their own, thereby risking 'medically induced poverty'. This case study analyzes the emergence of a situation of economic vulnerability generated by a public health policy that is nevertheless globally appropriate in terms of accessibility and epidemiological effectiveness. Because of the gap between the rationales of institutions at the international and national levels and those of people 'on the ground', a strategy that has been defined as progress in terms of equity is interpreted as a regression creating inequality. This situation stems from several determinants analyzed in this article: rapid and poorly managed transition from one strategy to another, different perceptions of acceptable risk levels, and inadequate communication of information by care providers. (Global Health Promotion, 2013; 20 Supp. 1: 39–44).

Keywords: breastfeeding, health policies, HIV, medically induced poverty, PMTCT, Senegal, transitions

Introduction

The dominant thinking in international public health over the second half of the twentieth century held that the function and intended effect of public policies and healthcare systems were to instill equity into inegalitarian social systems based on the principles of medical ethics and the right to 'health for all' (1). Empirical observation showed the limitations of this model with respect to those populations who were most vulnerable because of inferior status (social, economic, citizenship, etc.). It also revealed that healthcare policies and systems themselves generated socioeconomic vulnerabilities. The North American critical medical anthropology movement and its francophone counterpart of public health anthropology studies have been involved in analyzing this production of vulnerability, particularly in clarifying the logics of the actors in context – for example, those 'on the ground' in health services in local social cultures (2,3). In particular, these studies have examined how processes of categorizing populations for disease management, which are inherent to biomedical institutions, have played a role in producing inequalities, specifically in West Africa (4,5). While public health analyses were exposing the 'medical poverty trap' induced by the costs of care and 'catastrophic expenses' (6), anthropologists were analyzing the underlying 'politics of life' around key concepts such as the 'exclusion' or 'triage' of patients (7).

These analyses focused on policies and programs, but less often on the social impacts created by their changes or transitions, except for studies on resistance to treatment innovations. The HIV epidemic has exposed this issue because rapid innovation in this field has presented both institutions and individuals (persons living with HIV and health professionals) with many changes in prophylactic and therapeutic strategies over a short time: in the case of prevention of mother-to-child transmission (PMTCT), three successive strategies

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emerged within 12 years. This article presents a monographic study of a situation of socioeconomic vulnerability linked to that succession of PMTCT strategies. Based on our analysis of ethnographic data collected in Senegal in 2010 and 2011, we discuss the determinants of the genesis of this vulnerability.

Case study

Dakar, 2011: Mr and Mrs Sow[i] have just had a second child. They have known for more than seven years that they are HIV carriers, and they are in good health with antiretroviral treatment. Their first child, born three years ago, was fed with infant formula; Mrs Sow followed the measures laid out by the national PMTCT program, which provided substitutes for breast milk. Now, in 2011, the national strategy is based on pharmaceutical prophylaxis and the program still provides antiretrovirals, but no longer supplies milk substitutes. This was the only information provided to the couple during the pregnancy. Mr and Mrs Sow decided to buy the infant formula themselves, since they consider it to have been essential in protecting their first child. The household is not living under conditions of social exclusion: Mr Sow has a salary. Nonetheless, the cost of infant formula, which can only be purchased in pharmacies that only sell infant formula produced by multinational companies, represents more than half of Mr Sow's income, even though his wages are above the legal minimum wage for Senegal[ii]. To cover this cost, Mr and Mrs Sow have kept all other spending to a strict minimum, even saving on food and fuel by preparing their meals only once a day. Mr Sow has also embarked on a quest that involves making the rounds of associations that support people living with HIV (PLHIV) to obtain a few tins of formula, when available, which also represents an investment of time and money into getting around. During the nine months of formula feeding, Mr and Mrs Sow have had to seek financial assistance from their social network on several occasions to cover other expenses for medical prescriptions, and to allow Mrs Sow to be 'released' from a hospitalization[iii]. Purchasing infant formula has subjected Mr and Mrs Sow to the constant concern of having to 'find the means' to cover daily necessities, which is one way of defining the experience of poverty in Senegal (8). Theirs is a situation of socioeconomic vulnerability: they have taken on debt with no certainty regarding their future capacity for repayment, which has altered their status and social relationships. They have been able to avoid interrupting their baby's formula feeding thanks to the generosity of the infectious diseases physician who follows them and to Mr Sow's network of acquaintances in the international organization where he works. Mr and Mrs Sow's story is not unique: the associations report similar precarious situations induced by parents' need to purchase infant formula.

International prevention strategies and how they are perceived locally

To understand the genesis of the Sow family's socioeconomic vulnerability, we first need to look at the international policies regarding PMTCT and how they are applied in Senegal.

After HIV transmission through breastfeeding was described in 1985, developed countries immediately adopted formula feeding for all exposed infants. For Southern countries, a global prevention policy was only defined in 1998, which invited women to choose, depending on their health and social environment, between two strategies that either eliminated the HIV risk (formula feeding) or reduced the transmission rate (exclusive breastfeeding with early weaning). In 2010, the United Nations agencies revised this policy by placing greater emphasis on antiretrovirals and leaving the decision on infant feeding to the national authorities. The use of exclusive breastfeeding 'with ARV protection' was chosen by African countries because it offered two advantages: it guaranteed economic accessibility, and it was more acceptable because it helped avoid stigmatization in countries where prolonged breastfeeding is the norm. The new antiretroviral treatment protocol helped reduce the overall HIV transmission rate to 5% in cases of breastfeeding and 2% in cases of formula feeding (9), and made it possible to treat the mothers' own health more systematically than before. The national strategy adopted in Senegal in June 2010 has been progressively implemented.

While antiretrovirals have been very positively accepted *a priori* by PLHIV, and the currently recommended feeding option appears to be the easiest to implement at the national level, the new strategy has elicited a certain amount of resistance

and protest. These come primarily from the national women's association, ABOYA (from a Wolof expression meaning 'united in hope'), which develops advocacy, support and mutual aid activities for women and children living with HIV. These women are demanding the right to choose for themselves the method of feeding their infants, which would mean having the program continue to supply infant formula, since most women in the program could not afford to purchase it. In their view, the new strategy does not totally eliminate risk and represents a step backward in terms of the service provided by the program, since infant formula is no longer provided. While WHO considers the strategy to be based on expanded use of antiretrovirals, the women see it essentially as transferring the costs of formula to them, as well as presenting other disadvantages, analyzed elsewhere (10).

Analysis: transition and continuity

A critical transition

The emergence of resistance in Senegal, as opposed to the other West African countries, is due to the fact that this was the only country that had, from 2002 to 2009 without interruption, given mothers the effective ability to practise artificial feeding by providing formula and the necessary devices. Thanks to the involvement of healthcare services and associations in Dakar and its suburbs, which followed the women and offered families both psychological and social support, it was possible to provide formula feeding even under difficult socioeconomic conditions while avoiding the deleterious nutritional and infectious impacts experienced in other African countries. The majority of mothers living with HIV in the PMTCT program had benefited from formula well into 2009.

In 2010, there were several months of stock shortages of infant formula due to the complexity of the administrative purchasing procedures at the Ministry level, followed by a complete breakdown in the supply when international funding agencies were no longer willing to fund infant formula in light of the new strategy. The lack of preparedness or of any transition measures in the healthcare services raised protest, especially from the physicians and associations who had to contend with the situation of caring for infants when formula was suddenly no longer available. Moreover, not all care providers were trained in the new strategy when it was implemented, and they did not yet understand its scientific rationale. Finally, no preparations were made to modify the messages delivered by care providers and no specific measures were planned for women who, like Mrs Sow, had already had the experience of formula feeding a child who was not infected, all of which exacerbated the problems of acceptability.

This ineptly managed strategy change was interpreted by the associations as being due to cutbacks in international funding for the fight against AIDS, within a national political context of a public governance crisis that encouraged defiance. According to certain association members, the stock shortages were intended to 'prepare people's minds' for an end to the provision of infant formula. Association advisors reported that some pregnant women, deducing that the healthcare services would no longer be able to help them, stopped coming in for prenatal visits.

Acceptable HIV risk levels and provider–patient communication

For the Sow couple, and for members of ABOYA who spoke in individual or group interviews for the survey, as well as in public, the new strategy's effectiveness in reducing the overall risk of mother-to-child transmission of HIV is not conclusive. They emphasize that breastfeeding an infant with the knowledge that the virus might be transmitted is not acceptable for any mother, no matter what the residual risk is under antiretrovirals, especially when there is a known means of totally eliminating that risk. The ABOYA advisors continue to recommend infant formula, considering maternal breastfeeding to be a last-resort measure imposed on mothers without resources.

On the other hand, the information provided by health services professionals does not put much emphasis on the notion of probability or on comparing rates of HIV risk. This is a common feature of West African health services, where information about health is essentially limited to what are called *causeries*[iv]. Patients are given orders more often than specific and complex knowledge. Thus, some women reported that 'before, they said

not to breastfeed because of the virus', and now these women were troubled by the radical change in discourse that, in their view, discredited the care providers. For couples who already had a child who was formula fed and not infected, these elements were combined with the psychological dimension of putting a much-wanted child at risk and with their own previous experience of effective prevention.

Discussion: transition, inequitable health product and mass strategy

Unlike the Sow couple, other mothers adopted the new strategy of protected breastfeeding; this was particularly the case among primiparous women or those followed at decentralized PMTCT sites. The associations' discourses may progressively incorporate protected breastfeeding, which mothers will adopt more readily once there are enough cases of children not being infected thanks to the new strategy, to serve as examples. Without a doubt, the change would have been facilitated by better transition management, which could have included: maintaining the provision of substitute products for an intermediate period to allow infants who had already been started on formula to continue without risk; having care providers deliver consistent and appropriate messages, adopted before the change in strategy; and offering specific measures for mothers who had already practised the previous strategy. Policies and programs are introduced into the health services micro-culture, where relationships between providers and patients are built upon existing practices and values that cannot be changed overnight 'by decree', but rather require time to reconfigure ways of thinking and doing.

This case study is concerned with infant formula, a 'health' product with a very particular status in terms of its political and healthcare history that keeps its cost very high. The business strategies of companies and, indirectly, the fight – particularly by UNICEF – against abusive uses of formula have prevented the development of opportunities for equitable supply and access similar to those created for other products, such as condoms and drugs. The socioeconomic vulnerability induced by the purchase of infant formula also applies to households that are obliged to obtain it for other reasons: mother's inability to breastfeed due to agalactia, mother's absence, postpartum psychosis, etc. Other health products, rendered 'inequitable' because of high cost or problems of accessibility, could likewise generate socioeconomic vulnerability for those who must obtain them.

Finally, while Mrs Sow's desire to avoid all risk of HIV transmission via breastfeeding was rational, her good immunity level under antiretroviral treatment made the use of infant formula superfluous, since the level of risk in her case was a priori minuscule. For their decision to be appropriate from a biological standpoint, Mr and Mrs Sow needed a medical opinion that would tailor to their particular case a public health strategy that had been defined for the general population. 'Mass' 'strategies can thus create expenses that are catastrophic and not very useful at the margins of their target populations, when the medical infrastructure is inadequate, poorly coordinated, and incapable of tailoring collective recommendations to the specific needs of individual situations. This is not simply a matter of a structural insufficiency of human resources in African health services; rather, this expresses the fact that health policies still too often consider persons targeted by such programs to be 'empty receptacles'[v] who will adopt medical recommendations on the spot without interpreting them, as if they had no experience, no other source of information or framework for interpretation, and no memory.

Conclusion

The history of the prevention of mother-to-child transmission of HIV via breastfeeding has been punctuated by adjustments in the relationship between the PMTCT program and socioeconomic inequalities or vulnerabilities. This reflects the fact that there is no single preventive strategy that is easily accessible and applicable everywhere, such that it is left to the biomedical authorities to negotiate the complexities of redefining the level of risk to be managed by the healthcare system, which will differ depending on the populations, the environments and the available resources.

In the 1990s, before the establishment of national programs, only mothers with significant social and economic capital were informed about HIV transmission and had access to infant formula. In the first decade of the 2000s, Senegal's PMTCT program was able to eradicate the risk of HIV

transmission through breastfeeding by using infant formula in all categories of the population, including the most socioeconomically vulnerable, wherever engaged health professionals and associations were able to provide support. Now, since 2010, the program has offered everyone a strategy that reduces risk, and leaves it to individuals at the household level to take responsibility for eliminating that risk by using formula feeding. The socioeconomic inequalities related to prevention, which were major before 2000, reappeared, with a much more limited impact on HIV risk. Parallel to this was the emergence of the risk of socioeconomic vulnerability created by the cost of infant formula, which was now to be paid for by the families. These impacts at the system's 'margins' do not correspond to processes of exclusion or triage, but rather have to do with assigning to the healthcare system, 'civil societies' and families the responsibility for implementing a prevention strategy. Under national programs, the new strategy reduces mother-to-child transmission of HIV to a 5% risk level, which is characterized as 'eradication' (12). The responsibility for providing access to infant formula, that would reduce this rate to 2%, is not taken by the health system: this appears to go against the ambitious eradication policy announced for 2015. These decisions are dependent upon complex trade-offs between costs, benefits, and infectious and nutritional risks associated with the different strategies, all estimated by institutions that follow different logics – based notably on their scale of intervention and their target health problem, as was demonstrated by the analyses of incompatibilities between vertical programs, especially with regard to breastfeeding and HIV (13). These decisions are also based on implicit assumptions regarding the attitudes of the populations, including the worst-off, who are expected to be economically rational and not to engage in formula feeding if it would seriously compromise their resources. These trade-offs reveal the presence of 'politics of the possible', which define objectives according to what seems feasible based on contexts and populations, whereas the persons involved may wish to achieve more ambitious objectives, and sometimes do. Strategies that may appear realistic at the collective level but are inadequate for the persons involved may pave the way for the latter to move toward medically questionable initiatives, deleterious social or economic consequences, or recourse to services outside the biomedical healthcare system.

The very particular situation presented in this article calls attention to the interpretation of health policies at the country level and to the iatrogenic potential for divergences from the 'visions' of the international community, particularly with regard to questions of scale. The United Nations agencies' new strategy replaces other strategies that were poorly effective, since in 2010 the number of infants newly infected by mother-to-child transmission was still 350,000 in sub-Saharan Africa. The antiretroviral prophylaxis now recommended appears more feasible, on an international scale, than behavioral strategies, and seems to be applicable by a greater number of women in Africa, although it comes at the cost of reduced efficacy in terms of HIV transmission for Senegalese mothers[vi]. Here we see one of the long-standing dilemmas of public health: the levelling-off of a strategy at the population level may entail regression for a sub-population that, thanks to a certain context or to particular conditions in the performance of health interventions, had managed to derive the greatest benefit from the previous strategy. This is a constant dilemma during the phase of decentralizing programs to suburban and rural areas, which implies certain equity trade-offs when programs are applied to very inegalitarian societies or environments.

This raises another question, which is that of the current relations between the national and international levels when it comes to defining health policies. At a time when the capacity to implement national policies is dependent on international experts within the funding agencies, only a political science analysis of governance mechanisms will clarify what role states' sovereignty might play in this matter. To what extent are states able to interpret public health strategies according to specific modalities and ultimately to tailor them to different contexts within the country, and to what extent must they apply those that have been defined using criteria from the regional level, or from the subregional level? It will be instructive, in this respect, to look at how they handle the problem of a transition that can potentially lead to socioeconomic vulnerabilities, which is the subject of this article, at different levels of public health institutions, from the local to the international.

Several structural aspects of health systems and other determinants have given rise to the health expense we have analyzed here that leads to socioeconomic vulnerability: poorly managed transition between strategies; bringing into play an 'inequitable' health product; poor quality of information transmitted by care providers; reduction in the resources available to patients from the healthcare system; breakdown in medical management at the individual level; and standardization of health strategies. At a time when international funding for the fight against pandemics is declining, this form of medically induced vulnerability warrants examination.

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Notes

i. This is a pseudonym. The data were collected as part of the ANRS 1215 study conducted by the Research and Training Centre of the clinical management unit at Fann Hospital, coordinated by Drs Bernard Taverne and Ibra Ndoye, funded by France's *Agence Nationale de Recherches sur le Sida et les hépatites virales* (National Agency for Research on AIDS and Viral Hepatitis).
ii. Mr Sow reported a minimum monthly cost of 28,000 F CFA (43 €) for cartons of infant formula and mineral water, while his monthly wage was 52,000 F CFA (79 €); the guaranteed minimum wage is 36,243 F CFA (55 €). The cost for infant formula rises in the first six months depending on the infant's consumption, then decreases according to the proportion of formula in the infant's diet. The cost of fuel for preparing the formula was not included in this estimate.
iii. Some Senegalese hospitals engage in the illegal practice of taking patients "hostage" (or confiscating their identity papers) until the families have fully paid for the services provided.
iv. A *causerie* is a kind of lesson delivered by health workers to mothers who listen like pupils, following the usual pattern in West African francophone countries.
v. This notion, put forward by Polgar from 1962 to make professionals aware that individuals in target populations are not completely ignorant people waiting expectantly for scientific knowledge, is one of the historical concepts explaining the importance of the anthropological dimension of public health (11).
vi. There is no data available to quantify mother-to-child HIV transmission in the different phases of the Senegalese program.

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